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**TYPE 1 DIABETES IN ADOLESCENCE
– A SHARED RESPONSIBILITY**

by

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A thesis submitted in partial fulfilment of the requirements for the degree
of Doctor of Clinical Psychology.

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Contents

	Page
Contents	
List of Figures	
List of Tables	
List of Appendices	
Acknowledgements	
Declaration	
Summary	
1. LITERATURE REVIEW	1
1.1. Abstract	2
1.2. Introduction	3
1.3. Responsibility and individual factors	9
1.4. Responsibility and interpersonal factors	14
1.5. Responsibility and outcome	18
1.6. Summary of the literature and proposal of theoretical model	25
1.7. Methodological limitations	30
1.8. Implications for practice and research	33
1.9. References	36
2. PAPER 1	46
2.1. Abstract	47
2.2. Introduction	49
2.2.1. Diabetes in adolescence	49
2.2.2. Self efficacy	49
2.2.3. Social support from family	51
2.2.4. Responsibility	52
2.2.5. Social support from friends	53
2.2.6. Aims	54
2.3 Method	54
2.3.1 Participants	55
2.3.2 Procedure	57
2.3.3 Measures	58
2.4 Results	62

2.4.1	Descriptive findings	62
2.4.2	Prediction of dietary self care	64
2.4.2.1	Early adolescence	65
2.4.2.2	Mid-late adolescence	67
2.5	Discussion	69
2.6	Methodological considerations	72
2.7	Treatment implications	73
2.8	Future research directions	74
2.9	References	75
3.	PAPER 2	85
3.1.	Abstract	86
3.2.	Introduction	87
3.3.	Aims	91
3.4.	Method	91
3.4.1.	Participants	92
3.4.2.	Sample characteristics	93
3.4.3.	Procedure	93
3.4.4.	Analysis	95
3.5.	Results and discussion	97
3.5.1.	Emotions	101
3.5.2.	Identifying with illness	105
3.5.3.	Support	111
3.5.4.	Long term management	116
3.6.	Limitations and suggestions for further research	120
3.7.	Conclusions and implications for practice	122
3.8.	References	126
4.	REFLECTIVE REVIEW	135
4.1.	Introduction	136
4.2.	Recruitment	136
4.3.	Ethical considerations	137
4.4.	Methodological issues	139
4.4.1.	Quantitative vs. Qualitative	139
4.4.2.	Impact on participant	140
4.5.	Personal reflections and learning	142

4.5.1. Issues of identity and the practitioner-researcher	142
4.5.2. Self efficacy	143
4.6. A final note	144
4.7. References	146

List of Figures

- 1 Theoretical framework for role of responsibility in diabetes management for adolescents with type 1 diabetes.

List of Tables

- 1.1 Summary of research studies examining association between responsibility for diabetes self management and individual factors.
- 1.2 Summary of research studies examining association between responsibility for diabetes self management and interpersonal factors.
- 1.3 Summary of research studies examining association between responsibility for diabetes self management and health outcome variables.
- 2.1 Table summarising demographics of sample.
- 2.2 Comparison of parent and child ratings, across age groups, for the main study variables
- 2.3 Results of hierarchical multiple regression with early adolescent group
- 2.4 Results of hierarchical multiple regression with mid-late adolescent group
- 3.1 Summary of the IPA Analysis process
- 3.2 Table of the master and sub themes from the child focus group
- 3.3 Table of the master and sub themes from the parent focus group
- 3.4 Table of the domains shared by the two groups

List of Appendices

1. Ethics Committee Approval – Coventry University
2. Ethics Committee Approval – MREC
3. Letter of invitation – Paper 1
4. Information sheet (Young person aged 12-16 years of age)
5. Information sheet (Young person aged 17-18 years)
6. Consent form (Young person aged 12-16 years of age + Parent)
7. Consent form (Young person aged 17-18 years)
8. Information sheet (Parent)
9. Consent form (Parent of young person aged 17-18 years)
10. General Demographic Information Sheet (Adolescent)
11. General Demographic Information Sheet (Parent)
12. Dietary self efficacy questionnaire (Adolescent)
13. Dietary self efficacy questionnaire (Parent)
14. DSSQ–Family (modified)
15. DSSQ-Friends (modified)
16. PAID-Teen (modified)
17. PAID–Parent (modified)
18. Summary of Diabetes Self Care Activities Scale (Adapted)
(Adolescent)
19. Summary of Diabetes Self Care Activities Scale (Adapted) (Parent)
20. DFRQ
21. Ethics Committee Approval – Coventry University
22. Ethics Committee Approval – Northampton Trust
23. Letter of invitation – Paper 2
24. Information leaflet (Adolescent and Parent)
25. Consent form (Adolescent and Parent)
26. Interview questions for Adolescent focus groups
27. Interview questions for Parent focus group
28. Consent form for audio recording (Adolescent)
29. Consent form for audio recording (Parent)
30. Example of IPA Stage 1 & 2

31. Example of IPA Stage 3
32. Example of IPA Stage 4 (Table of themes)
33. Example of IPA Stage 5 (Master list of themes)
34. Diabetic Medicine – Author guidelines
35. British Journal of Health Psychology – Notes for contributors
36. Qualitative Health Research – Author guidelines

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Declaration

This research thesis was conducted under the supervision of Dr Delia Cushway and Dr Arie Nouwen. Authorship of any papers will be shared with these supervisors. The thesis is my own work. This thesis has not been submitted for a degree to any other university.

Summary

Type 1 diabetes affects over 16,500 children in the UK. For these young people, care is needed to maintain 'near normal' blood glucose levels in order to relieve the unpleasant symptoms of high and low blood glucose. Although good metabolic control may decrease the risk of severe long term complications, adolescents often have difficulty juggling all the aspects of a complex and demanding treatment regimen, and poor adherence is commonplace.

The literature review proposes a theoretical framework for understanding the role of responsibility in the management of type 1 diabetes during adolescence. The pattern of responsibility is explored in relation to the individual and their interpersonal context. In terms of health outcome, the effects of individual and shared responsibility are considered, necessitating a balance between the adolescent's assumption of responsibility and their level of parental involvement. Suggestions for clinical practice are discussed, methodological limitations raised, and future research opportunities identified.

The role of dietary self efficacy in predicting self care during adolescence is established. Using data for two distinct phases of adolescence, paper 1 examines whether social support from family and friends makes any additional contribution to the prediction of dietary self care, over and above that of self efficacy. For the younger group (aged 12-13), the prediction of self care is improved by better perceived support from friends. An interactive effect of shared family responsibility is also reported, confirming the importance of shared responsibility, between parent and child, to facilitate good self management as highlighted in the literature review. None of the variables are significant predictors of self care in the older group (14-18 year olds).

Paper 2 is exploratory in nature, and using Interpretative Phenomenological Analysis to review data collected by means of focus group interviews with adolescents and their parents. This study highlights how both child and parent share similar struggles in the management of this frightening illness, and provides an insight into the experience of coping from the contrasting perspectives of parent and child. Difficulties identifying with illness are discussed, with particular reference to the conflict integrating illness with the individual. The role of social support and issues regarding long term management, in particular the balancing of responsibility, are also addressed.

The reflective review discusses issues arising from the research which may be of benefit to other psychologists and researchers.

CHAPTER 1: LITERATURE REVIEW

Responsibility for diabetes self care in adolescence: A critique of the literature

This paper has been prepared for submission to Diabetic Medicine

(See Appendix – Author guidelines)

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Chapter One: Literature Review

Responsibility for diabetes self care in adolescence - A critique of the literature

1.1 Abstract

Aims

This article reviews the literature on responsibility for self care behaviours in adolescents with type 1 diabetes. The pattern of responsibility is explored in relation to the individual and their interpersonal context, as well as its effects on health outcome.

Method

Systematic review of the published literature. Data sources were Medline, Psychinfo and a hand search. Included studies were papers written in English published between the years 1980-2003.

Results

Seventeen papers fulfilled the criteria for inclusion; ten of these were cross-sectional, five were exploratory/descriptive, one was experimental, and one followed a longitudinal design. Six studies reported a positive relationship between age and level of responsibility. Four studies reported a positive relationship between parental involvement and levels of adherence and metabolic control, whilst another two studies contradicted these findings. These inconsistent results can in part be explained by differences between

studies in the measurement of key constructs and outcome variables. The assumption of responsibility carried benefits and barriers for both the adolescent and their parents.

Conclusions

Responsibility for diabetic care increases in line with other adolescent activities but the adolescent's sense of increased autonomy can lead to substantial diabetes related conflict, and negatively affect family functioning. A theoretical framework for the system in which responsibility interacts with personal and contextual factors to predict health outcome for the adolescent with type 1 is proposed. The continued involvement of parents is advocated, and the adolescent's involvement and control over decisions related to their own care is encouraged.

1.2 Introduction

This review explores the literature on responsibility and autonomy in adolescents with Type 1 diabetes, and its relationship with aspects of self-management and interpersonal dynamics.

Type 1 diabetes (Type 1) is a lifelong chronic illness characterised by the accumulation of abnormal levels of glucose in the blood as the pancreas fails to produce sufficient insulin. In the UK, for children under the age of 16, the prevalence of Type 1 is estimated at around 16,600 [1].

Young people affected with Type 1 require insulin injections to prevent acute complications resulting from abnormally high or low sugar levels. Type 1 is also associated with a number of long-term serious complications affecting neural, visual, and kidney functions. In order for the young person to successfully control this illness, a relatively complicated regimen is required balancing insulin dosage and administration, blood glucose monitoring, diet and exercise. Living with Type 1 can have a profound impact on well-being as well as physical ill health, and as with any chronic disease, a person's home life and position in society may come under pressure [2].

Effective diabetes management, and the achievement of as normal a blood glucose concentration as is possible, has been shown to be advantageous in increasing life expectancy and reducing the risk of complications [3-4]. The cornerstone of diabetes care is self management [5] - learning to live with the illness as well as how to control it within the context of one's life [6]. Achievement of adequate control relies heavily on the motivation and understanding of the condition by people with diabetes and their carers [7].

Adolescence is a period of development and transitions, combining more biological, psychological, and social role changes than any other stage of life except infancy [8]. These changes pose special challenges to the successful management of diabetes: hormones heighten the risk for metabolic

disturbances, increased diabetes knowledge may result in anxiety and fear about their illness, peer inclusion and independence become a significant priority [9], and both self-care adherence and metabolic control may be compromised. Holmbeck [10] proposes a model for the association between developmental change and outcome as mediated by the behaviour of significant others, and moderated by demographic and intrapersonal variables. Thus as the adolescent develops cognitively, they become better able to problem solve and consider the consequences and risks of their health behaviours. In this way, if the adolescent chooses to shift their energies away from diabetes self-management into achieving peer inclusion, then ultimately the support of these peers, and their role in encouraging adherence, will impact on health outcome.

Autonomy development, facilitated by the assumption of responsibility, is an important element of adolescence yet there is scant research looking at its course, context, and association with interrelating factors. Increasing autonomy occurs in every aspect of the adolescent's life. It is popularly perceived as of critical importance [11], but for the young person with type 1, there is a great potential for conflict between diabetes care and other aspects of his/her life. Indeed, total autonomy, or complete responsibility for the range of behaviours advocated in diabetes management, may lead to a deterioration in both self-care adherence, and metabolic control [12-14].

Adolescence marks a transition, with responsibility shifting from the parents, into the hands of the adolescent. They are expected to assume greater responsibility for tasks of the treatment regimen [15-16], which they may, or may not, be in a position to handle effectively. It is unclear how and when these roles in the self management process alter, but there is clinical value in monitoring the transfer, and encouraging effective communication between parent and child [17].

Studies of adolescents with diabetes have established relationships between responsibility and various aspects of individual difference, health outcome (metabolic control and adherence), and interpersonal relationships. They have not, however, provided an explanation for how these relationships operate nor how they interact with one another. This review seeks to provide a basis for understanding the complex issue of responsibility for diabetes management throughout adolescence. The objectives are: (1) to explore the association of adolescent responsibility and individual factors; (2) to explore the association of adolescent responsibility with interpersonal and contextual factors; (3) to explore the association of adolescent responsibility specifically with health outcome; and (4) to propose a theoretical framework for the system in which responsibility interacts with personal and contextual factors to predict health outcome. Given that many of the methodological criticisms will be shared between the studies, these sections will be followed by (5) a methodological critique including implications for practice and future research.

Articles were found through a search of the MEDLINE and PSYCHINFO contents databases using the search terms *diabetes* and/or *child/young person/adolescent* in combination with *responsibility and/or autonomy* for the years 1980-2003. In addition, a further hand search of the bibliographies of these references was undertaken. Inclusion criteria were studies which (i) investigated an adolescent (12-18 years) population with type 1 diabetes, (ii) assessed as an independent measure either responsibility or autonomy and (iii) were published in peer reviewed, English language journals. Studies were not included if they were theoretical or offered reviews, although these latter articles were used in considering the theoretical and clinical implications of the literature.

It is difficult to clarify the concept of responsibility. Throughout the literature the lack of uniform terminology and assessment is striking, and the case for an appropriate definition of diabetes related responsibility is long overdue. In the most part, this is an artefact of the language. There are many definitions for the term responsible, combining the concepts of capability and accountability. The most useful, for the purpose of clarity, is provided by the Oxford English Dictionary [18] as “capable of fulfilling an obligation or trust; reliable, trustworthy, of good credit and repute”. Interestingly, just as for autonomy, (“liberty to follow one’s own will, personal freedom” [18]), as a concept, responsibility makes no mention of action, yet self-management, and adherence, are a fundamental part of the regime for diabetes care. The

assessment of responsibility presents further ambiguity. The DFRQ [19] is a well used and valid research tool which measures responsibility for a broad range of diabetes tasks, as well as patterns of agreement in the division of tasks, between parent and child. The assessment fails, however, to measure the actual performance of these tasks which is of crucial importance clinically. More recently, reflecting the omission of action in responsibility, Hanna and Guthrie [20] propose investigation of behavioural autonomy, a concept including both independent functioning and decision making [11].

For the purpose of this review, the definition of responsibility will be broadened to incorporate the individual's decisions and actions, as an extension of their capability and reliability.

1.3 Responsibility and individual factors

Table 1.1 presents all of the studies which have examined the association of individual factors with the concept of responsibility for diabetes self-management as well as their principal methodological characteristics.

Table 1.1 Summary of research studies examining association between responsibility for diabetes self management and individual factors.

Investigation	Design	Assessment	Summary of results
Anderson et al., 1990 [19]	Cross-sectional; 121 cases (6-21)	Structured interview, DFRQ (Parent, Child), HbA1c.	Significant association: Age and duration strongest predictors for General Health and Regimen tasks (Increasing age and duration associated with increased responsibility. Increasing age associated with increased agreement in parent-child responsibility for diabetes related tasks). Sex of child strongest predictor for Social Presentation of diabetes (girls report more responsibility).
Anderson et al., 2002 [12]	Cross-sectional; 104 cases (8-17)	Structured interview, DFRQ (Parent, Child), Diabetes Conflict Scale ¹ , Diabetes adherence rating scale ² , HbA1c.	Significant association: More parental involvement with both insulin treatment and blood glucose monitoring for younger patients (aged 8-12) in comparison to older group (aged 13-17).

Investigation	Design	Assessment	Summary of results
Drotar & Ievers, 1994 [15]	Cross- sectional; 52 cases (Mothers of children aged 4-14 years)	Structured interview, DFRQ (Parent) or Cystic Fibrosis Family Responsibility Questionnaire (CFFRQ) ³ , Highland Dependency Questionnaire (HDQ) ⁴ .	Significant association: Age group associated with higher levels of children's independence in assuming treatment-related responsibility. Independence in treatment related responsibility highly related to general independence.
Hanna & Guthrie, 2003 [20]	Cross- sectional, 34 cases (11-18)	Questionnaires: Adaptation of DFRQ. Daily & Non daily Diabetes Management Checklists, Independent Functioning Checklist, Independent Decision Making Checklists for daily/nondaily diabetes management and typical activities. HbA1c	Significant association: Independent functioning differed significantly between stages of adolescence.
Ingersoll et al., 1986 [21]	Cross- sectional, 41 cases (12-21)	Questionnaires: Insulin adjustment, Test of general knowledge of diabetes ⁵ , Perceived control, WRAT ⁶ , Paragraph Completion method ⁷ , HbA1c.	Significant association: Linear relationship between age of the adolescent and parental adjustment of insulin (not related to illness duration).
La Greca et al., 1990 [14]	Cross- sectional, 40 cases (7-17)	Questionnaires: Responsibility (Mother), Diabetes Knowledge Test (Child, Mother), Adherence (Physician rated). HbA1c.	Significant association: Total responsibility score positively correlated with youngster's chronological age.

Investigation	Design	Assessment	Summary of results
Miller & Drotar., 2003 [22]	Cross- sectional, 82 cases (11-17)	Questionnaires: Pubertal Development Scale ⁸ , Oppositional behaviour ⁹ , Decision about Diabetes Treatment Scale ¹⁰ , Diabetes Conflict, Self- care Inventory ¹¹ . HbA1c.	Significant associations: Positive relationship between pubertal status and adolescent decision making autonomy. Positive relationship between adolescent decision making autonomy and diabetes related conflict. Discrepancies between adolescent and mother perceptions of adolescent autonomy related to greater maternal report of diabetes related conflict.

¹ Diabetes Family Conflict Scale [23] ² Diabetes adherence rating scale [24] ³ Cystic fibrosis family responsibility questionnaire [15] ⁴ Highland dependency questionnaire [25] ⁵Test of general knowledge of diabetes physiology and its management [26] ⁶ Wide Range Achievement Test [27] ⁷ Paragraph Completion Method [28] ⁸ Pubertal Development Scale [29] ⁹ Category C of Adolescent Symptom Inventory-4 [30] ¹⁰ Deciding about Diabetes Treatment Scale [31] ¹¹ Self-care Inventory [32].

In their cross sectional study, Anderson, Auslander, Jung, Miller & Santiago [19] report scores of both mothers and children on the total Diabetes Family Responsibility Questionnaire (DFRQ) and all its subdomains (General Health, Regimen tasks and Social presentation) to be strongly associated with age, and by association with that, disease duration. A number of subsequent studies provide support for the association between increased adolescent responsibility, reduced parental involvement, and chronological age [14-15,20-22].

Older children assume greater responsibility for treatment-related tasks. For example, Drotar and Ievers [15] found that the percentage of health care responsibilities performed solely by the parents of children with Type 1 decreased significantly from 70-79% (ages 4 to 7) to 32-37% (ages 11 to 14).

These age related trends in independence were especially pronounced on tasks directly related to treatment regimens such as giving injections or noticing the signs of a reaction. Tasks involving interaction with clinic or teaching staff remained largely the responsibility of the parent, even in the older group. Further studies add that mothers retain the responsibility for seeing that proper foods are eaten, and at the correct time, irrespective of age [14].

As well as the overall reporting of responsibility, the division of diabetes related responsibility, and in particular discrepancies in this reporting, is linked with age. Anderson et al. [19] report that confusion about the division of responsibilities between parent and child, resulting in some self-management tasks being unaccounted for, is greater amongst younger children. Comparing pairs of data on the DFRQ, they found that the number of items for which neither parent nor child assumed responsibility, reduced over time.

In summary, the literature provides generally consistent support for a relationship between increasing age and responsibility [14-15,19-22]. As the child grows older, there is also less confusion about the division of this responsibility, and it becomes more likely that there is accountability across the range of regimen tasks recommended for diabetes care. The young person's responsibility for diabetes tasks runs in parallel to their engagement within other domains of their life. So those young people holding a greater responsibility for managing their treatment regimens, are more independent in

managing non illness related responsibilities and engaging in typical adolescent activities [15,20]. The literature offers no indication of the factors involved in the process of determining whether responsibility can be given to the child as they grow older, but it has been hypothesized that the child's performance of these other responsibilities may provide a reliable assessment [13].

Whilst most researchers have failed to find any significant association between responsibility and gender [15], in the Anderson et al. [19] study, mothers reported higher responsibility levels for girls than for boys. These responsibilities related specifically to the social presentation of diabetes, including telling teachers, friends and relatives about their illness. These reports may be a reflection of parents holding higher behavioural expectations for their female children, or instead reflect a deeper maturity, since girls' adolescent development, in a broad capacity, occurs two years earlier than boys. This raises questions about the appropriateness of certain measurement variables within this population, for example using age as an indirect measure of puberty.

1.4 Responsibility and interpersonal factors

Table 1.2 summarises the six studies which have investigated responsibility for diabetes self-care in the context of interpersonal and family factors.

Table 1.2 Summary of research studies examining association between responsibility for diabetes self management and interpersonal factors.

Investigation	Design	Assessment	Summary of results
Anderson et al., 1999 [33]	Experimental, 85 cases (10-15)	Structured interview, Diabetes Family Conflict Scale, Diabetes Family Behaviour Checklist ¹ , HbA1c	Significant associations: Decrease in diabetes specific conflict for teamwork families. Decrease in unsupportive behaviour and negative behaviour for teamwork families.
Dashiff., 2003 [34]	Descriptive, correlational; 31 cases (12-15)	DFRQ (Mother, Father, Child), HbA1c.	Significant association: Mothers and Fathers reports of responsibility assumed by each member associated. Child and Fathers reports significantly different, Fathers attributed greater responsibility to Mother instead of the adolescent.
Hanna & Guthrie., 2000a [35]	Exploratory-descriptive (qualitative), 15 cases (11-18)	Semi structured interview.	Identified adolescents perceived benefits and barriers of assuming diabetes self-management for themselves and their parents.
Hanna & Guthrie., 2000b [36]	Exploratory-descriptive (qualitative), 15 cases (11-18)	Semi structured interview.	Identified perceived benefits and barriers of assuming diabetes self-management for themselves and their children.

Investigation	Design	Assessment	Summary of results
Hanna & Guthrie., 2001 [37]	Descriptive (qualitative), 16 cases (11-18)	Structured interview.	Identified categories of helpful and nonhelpful behaviours in ‘taking over diabetes care’ according to parents and adolescents.
Miller & Drotar., 2003 [22]	Cross-sectional, 82 cases (11-17)	Questionnaires: Pubertal Development Scale, Oppositional behaviour, Decision about Diabetes Treatment Scale, Diabetes Conflict, Self-care Inventory. HbA1c.	No significant associations: Greater discrepancies between mother and adolescent perceptions of decision making autonomy not related to worse adherence or control.

¹ Diabetes Family Behaviour Checklist [38]

Clinical observations suggest that parental involvement and reduced adolescent responsibility can lead to conflict and stress in the parent-adolescent relationship. Dashiff [34] explored reports by adolescents, mothers and fathers on the degree of responsibility assumed by each family member. All parties attributed a significant dependent-care responsibility to mothers but there were discrepancies between the reports of fathers and adolescents. Fathers failed to report the adolescent as primarily responsible for their diabetes, instead attributing this responsibility to the mother. Continuing this theme, Miller and Drotar [22] explored discrepancies in the perception of autonomy in adolescents and their mothers, and found that even after controlling for pubertal status, conflict was greater in families where the child reported a degree of autonomy markedly exceeding the mothers’ attributions.

The literature shows a significant relationship between adolescent decision-making autonomy, reduced parental involvement, and negative family interaction [22,33]. In-depth analyses of the division of responsibility within the family show a consistent dependant care responsibility for the mother, and a tendency for fathers to underestimate the degree of responsibility assumed by the adolescent [34].

Qualitative research expands the experience of transferring responsibility from parent to child and its meaning to the individual. Hanna and Guthrie [35-36] describe the perceptions of adolescents and parents as contributing factors in the transfer of diabetes management from parent to adolescent. Benefits and barriers are identified from both perspectives. The adolescents perceive having more freedom, approval from others, knowledge and confidence, as benefits, and the parents echo these descriptions with similar thoughts about their child's confidence, knowledge, freedom and control. As barriers, the adolescents perceive a burden of responsibility and lack of boundaries, again the parents share this view. The parents perceive a feeling of being relieved of burden, and gaining confidence and pride in their child's abilities, as beneficial. The adolescents also reflect on this lack of burden for their parents. In contrast, parents express concern about the loss of control and authority, dealing with consequences, and issues with lack of boundaries which they identify as barriers to the transfer of responsibility. This sense of parental worry, and guilt for not taking care of their children, was also expressed by the adolescents.

The positive and negative dimensions of support as related to the adolescent's assumption of diabetes management responsibility have been explored by Hanna and Guthrie [37]. By comparison across three dimensions of social support [39] they concluded that whilst adolescents and parents perceive the same categories of support as both helpful and non-helpful, the components of these dimensions were qualitatively different. This reflects the view that support has both positive and negative, or conflictual aspects, dictated by the individual and the temporal climate [40]. Thus whilst parents perceived their behaviours intended to improve performance, "just being there" and offering practical support, as positive, the adolescents focused on support offering practical help, incentive, encouragement and trust. These same support dimensions, directive guidance and tangible assistance, were also named as non-helpful by the same parents and adolescents, with comments highlighting this support as too forceful or direct, not needed, or unwanted.

In summary, assuming responsibility carries both benefits and barriers for the adolescent as well as their parents [35-36]. The burden of care is an unavoidable consequence of this responsibility which co-exists alongside more positive aspects. This is a source of particular concern for the parents, who struggle to balance the developmental needs of adolescence with the seriousness of diabetes, and the consequences of poor management.

Adolescents want parental help, but whether or not this guidance is well

received depends on varying degrees of directness and the perceived need for help.

The research literature raises two priorities for the management of diabetes: sustaining parental involvement, and minimising parent-adolescent conflict. In response to this, Anderson, Brackett, Ho, & Laffel [33] designed an office based intervention. Families were randomly assigned to one of three study groups receiving either a teamwork intervention encouraging parent-teen responsibility sharing, the provision of traditional didactic education with no specific focus on involvement, or standard care with no intervention. For the families who participated in the teamwork condition, there was a significant decrease in both diabetes specific conflict, negative family interaction and the perception of unsupportive parental responses. These results provide a tangible framework for encouraging more positive patterns of parent-child responsibility sharing, and also highlight the value of parent-adolescent partnership, reciprocity and cooperation [37].

1.5 Responsibility and outcome

There are three primary health outcomes in diabetes research; metabolic control measured by HbA1c, self-care adherence, and quality of life. The relationship between adolescent responsibility and metabolic control and/or self-care adherence has been the subject of 10 empirical investigations. At the present

time, quality of life and other psychological health outcomes have not been investigated in this context. Table 1.3 summarises the results of these studies.

Table 1.3 Summary of research studies examining association between responsibility for diabetes self management and health outcome variables.

Investigation	Design	Assessment	Summary of results
Anderson et al., 1990 [19]	Cross-sectional; 121 cases (6-21)	Structured interview & Questionnaires: DFRQ (Parent, Child). HbA1c.	Significant association: Increased responsibility associated with higher self-reported adherence. Disagreement in parent-child responsibility and lower adherence levels predicted poorer metabolic control.
Anderson et al., 1999 [33]	Experimental, 85 cases (10-15)	Structured interview, Diabetes Family Conflict Scale, Diabetes Family Behaviour Checklist, HbA1c	No significant associations: Trend for adolescents in teamwork group to improve HbA1c.
Anderson et al., 2002 [12]	Cross-sectional; 104 cases (8-17)	Structured interview and Questionnaires: DFRQ (Parent, Child), Diabetes Conflict Scale, Diabetes adherence rating scale, HbA1c.	Significant association: Lower parental involvement associated with lower levels of adherence and poorer metabolic control. Increasing age associated with decreased parental involvement (not associated with duration of diabetes), decreased adherence and poorer metabolic control.

Investigation	Design	Assessment	Summary of results
Dashiff., 2003 [34]	Descriptive, correlational; 31 cases (12-15)	Questionnaires: DFRQ (Mother, Father, Child), HbA1c.	No significant associations. Trend for association between prior poor control and adolescents perceptions that Mothers have more responsibility (and they have less). Trend for Fathers perception that Mothers have more responsibility when current metabolic control worse.
Gowers et al., 1995 [41]	Cross- sectional, 78 cases (12-16)	Questionnaires: FAD ¹ , Birleson Depression Inventory ² , HbA1c	Significant association: Good control linked to more parental involvement in insulin administration.
Hanna & Guthrie., 2003 [20]	Cross- sectional, 34 cases (11-18)	Questionnaires: Adaptation of DFRQ. Daily & Nondaily Diabetes Management Checklists, Independent functioning Checklist, Independent Decision Making Checklists for daily/nondaily diabetes management and typical activities. HbA1c	Significant association: Independent decision making correlated with good metabolic control.
Ingersoll et al., 1986 [21]	Cross- sectional, 41 cases (12-21)	Questionnaires: Insulin adjustment, Test of general knowledge of diabetes, Perceived control, WRAT, Paragraph Completion method, HbA1c.	No significant associations: Participation or non participation of parents not related to metabolic control, nor adherence.

Investigation	Design	Assessment	Summary of results
La Greca et al., 1990 [14]	Cross- sectional, 40 cases (7-17)	Questionnaires: Responsibility (Mother), Diabetes Knowledge Test (Child, Mother), Adherence (Physician rated). HbA1c.	Significant associations: Preadolescents assuming greater responsibility for charting glucose and eating meals/snacks had poorer levels of metabolic control.
Miller & Drotar., 2003 [22]	Cross- sectional, 82 cases (11-17)	Questionnaires: Pubertal Development Scale, Oppositional behaviour, Decision about Diabetes Treatment Scale, Diabetes Conflict, Self-care Inventory. HbA1c.	No significant associations: Greater discrepancies between mother and adolescent perceptions of decision making autonomy not related to worse adherence or control.
Wysocki et al., 1996 [42]	Cross- sectional, 100 cases (9-15)	Questionnaires: DFRQ, DIS ³ , CAS ⁴ , INS ⁵ , WRAT-R ⁶ , Self-care Inventory, DISC ⁷ , GHb.	Significant associations: Poorer treatment adherence with increased TYPE 1 self-care autonomy relative to psychological maturity.

¹ McMaster Family Assessment Device [43] ² Birleson Depression Inventory [44]; ³ Diabetes Independence Survey [45] ⁴ Das-Naglieri Cognitive Assessment System [46-47], ⁵ Interpersonal Negotiation Strategies Interview [48], ⁶ Wide Range Achievement Test – Revised [49], ⁷ Diabetes Information Survey for Children [50].

Anderson et al. [12] identify parental involvement as a significant predictor of adherence to blood glucose monitoring. In this way, youths reporting a low level of parental involvement, thereby assuming a large degree of responsibility themselves, have significantly lower levels of adherence and metabolic control.

Similar findings have been reported by La Greca et al. [14]. In their study, youngsters who assumed a large degree of responsibility for self care tasks such as charting glucose and eating meals on time, evidenced significantly poorer levels of metabolic control, despite controlling for adherence. Gowers et al. [41] comparison study, exploring family functioning for adolescents with and without diabetes adds to this body of evidence. They found that parents of well controlled children were significantly more likely to be involved in administering injections.

Wysocki et al. [42] have advanced the study by including the concept of whether the self-care autonomy presented by the adolescent is developmentally appropriate. Using a ratio of self-care autonomy to psychological maturity, the extent to which each child exhibits developmentally appropriate self-care autonomy, relative to objective assessments of their psychological maturity, is recorded. Excessive self-care autonomy was associated with adverse outcome in terms of low treatment adherence, hospitalisations and poor metabolic control. The incidence of these excessive levels of self-care autonomy increased with age, suggesting that the complete withdrawal of parental involvement is inappropriate at any stage in adolescence.

Despite the findings of the aforementioned articles, four studies have failed to find any statistically significant associations between responsibility and health outcome [21-22, 33-34] and a further two articles present apparently conflicting

results [19,21]. Miller and Drotar's [22] study incorporated an assessment of the adolescents perceived decision making autonomy, as well as a measure of the discrepancy between the adolescents report and that offered by their mothers. Neither were associated with either adherence or metabolic control, and the investigators highlight the limitations of this measure in reflecting the actual behaviours of the parent or adolescent which may be perceived as primarily automatic rather than conscious decisions. Dashiff's [34] study into family congruence for the perception of diabetes care responsibility, also failed to find a significant association between the respondent scores and metabolic control, but the study included only 31 participants and the age range was limited to 12-15 years.

Similar non-significant results have been reported by Ingersoll et al. [21] in relation to parent participation in adjusting insulin dose, and Anderson et al. [33] in their intervention study, facilitating the maintenance of parent-adolescent teamwork in diabetes management tasks. However, the former study [21] was limited by design, with the findings relating to only one aspect of the diabetic regimen. They did however document some interesting qualitative information, in that the discontinuation of parental responsibility was not balanced by the adolescents assuming responsibility for these tasks. The lack of statistically significant results from Anderson et al. [33] experimental study may have changed if they had used a different health outcome, such as self-care adherence instead of metabolic control, since their

results suggested a clinical trend for health improvement via better metabolic control. Due to the complex relationship between self care and metabolic control, the use of self-report measures of adherence are of greatest value for measuring health outcome [51].

Anderson et al. [19] and Hanna and Guthrie's [21], report that adherence and metabolic control, respectively, are better in adolescents with greater responsibility. These inverse results may be accounted by the wide age range employed in the Anderson et al. [19] study, which included young people from 6-21 years of age, Hanna & Guthrie's [21] small sample size, or their measure of responsibility adapted from the original DFRQ [19]. In the Hanna & Guthrie [21] study, whilst metabolic control was correlated with independent decision making for daily diabetes management, this did not relate to their actual independent functioning, and highlights the lack of correspondence between planned behaviours for diabetes self-care and their action. Whilst these young people asserted their autonomy in making decisions relating to their self care, this did not necessarily mean they engaged in the relevant activity.

In summary, giving due consideration to the range of studies exploring the interaction between responsibility for diabetes self-care and outcome, what is clear is that parental involvement is crucial in helping these young people achieve a good level of adherence or satisfactory metabolic control. The balancing of responsibility for these diabetes related tasks, or the optimum level

of parental responsibility is less clear but it seems important that the adolescent has a sense of involvement and control over decisions relating to their own care, even if this does not equate to active behaviours [21].

1.6 Summary of the literature and proposal of theoretical framework

At this stage we can only suggest a very broad framework with further refinement indicated for future research. A part of the framework proposed by the author (see figure 1) is loosely based upon a model presented by Holmbeck and Shapera [52] to illustrate how the primary developmental changes of adolescence have an impact on developmental outcomes, such as autonomy or responsibility. The adolescent's development occurs via the interpersonal context within which the whole model is embedded, necessitating a balance between the adolescent's assumption of responsibility and their level of parental involvement. The adolescent's developmental changes have both a direct and indirect effect on health outcome. In the same way, the health outcome of the adolescent feeds back into the responsibility for diabetic self-care, assumed by the adolescent and their parent, as well as to that adolescent's development more directly.

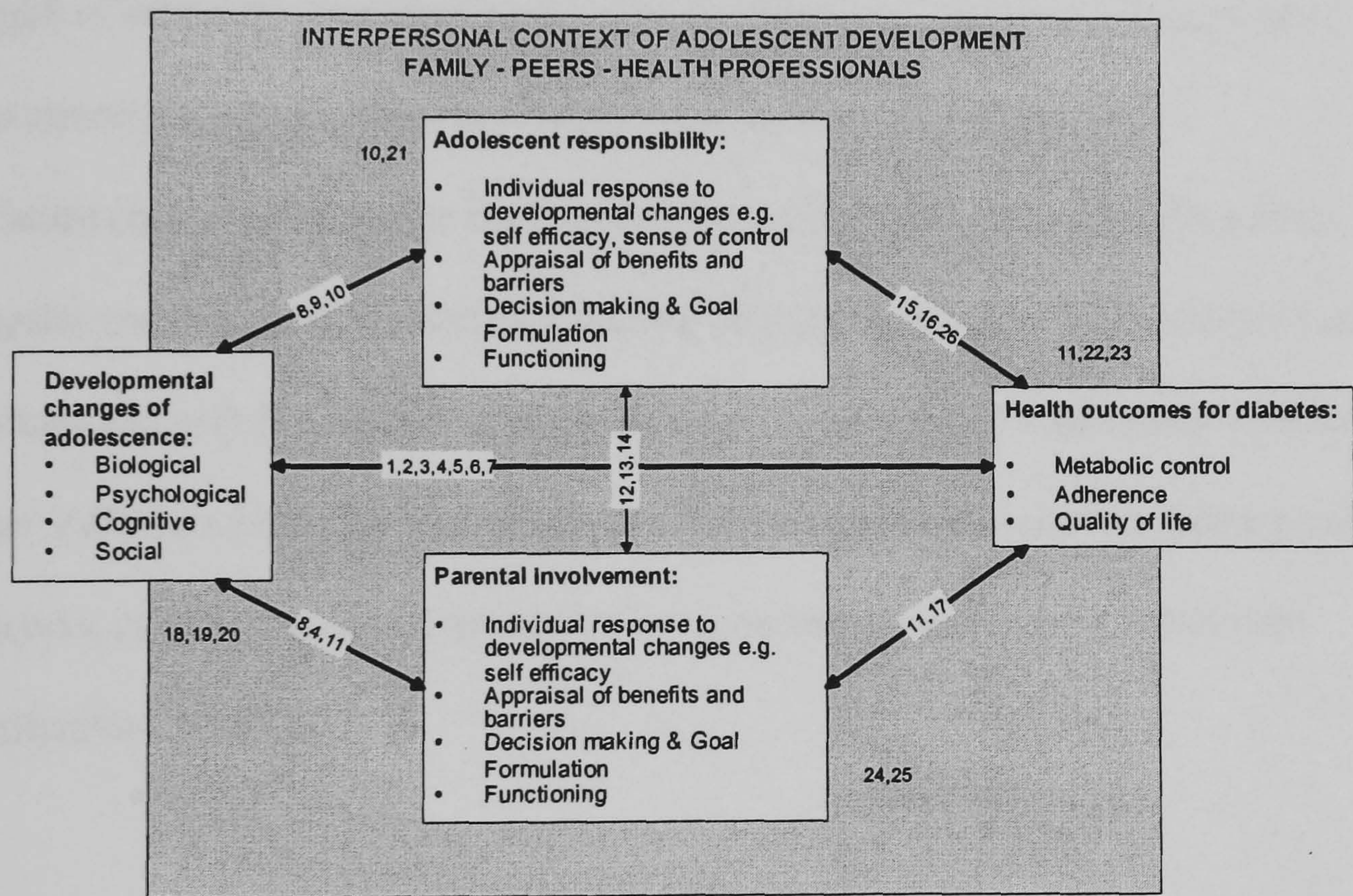
As an example, consider the following scenario. The adolescent ages and begins to take responsibility for a greater number of the tasks related to their treatment regimen. This decision has been influenced by their strong sense of

efficacy and control over their illness, and an analysis of the benefits and barriers to assuming this responsibility. Within the context of that adolescents development, and in considering the parents responses to these changes and the adolescents choices about their diabetes, family conflict may occur. The parents involvement may decrease substantially at this stage through exasperation, or as a result of this unresolved conflict. However, the adolescent may fail to assume responsibility for all of these tasks previously completed by their parent, perhaps because participation in peer group activities is more important, and consequently adherence and metabolic control worsens. If this blocks important life goals for the adolescent, such as needing good metabolic control to pursue a particular career, the adolescent may begin to feel depressed and anxious, withdrawing socially, and feeling unable to manage the responsibility demands of living with a chronic illness. The discrepancy between the adolescent's assumption of responsibility and the involvement of their parents may then grow wider, leading to further worsening of metabolic control, and the deterioration of family functioning.

The above example presents a somewhat negative outcome and assuming a contrasting position suggests the potential for positive outcome. In this way if parental involvement is maintained, with explicit communication and support facilitating the adolescent's development of responsibility adherence, metabolic control may be better controlled. To aid the reader, where the framework posits

relationships between variables, number annotations have been added. These guide the reader to the relevant scientific reference.

Figure 1 Theoretical framework for the role of responsibility in diabetes management for adolescents with type 1 diabetes.



¹Johnson et al., 1992 [53]; ² Wysocki et al., 1996 [42]; ³ Dantzer et al., 2003 [54]; ⁴ Ingersoll et al., 1986 [21]; ⁵ Brooks-Gunn 1993 [55]; ⁶ Whittemore et al., 2003 [56]; ⁷ Lloyd et al., 1993 [57]; ⁸ Anderson et al., 1990 [19]; ⁹ Drotar & Ievers, 1994 [15]; ¹⁰ Miller & Drotar, 2003 [22]; ¹¹ Anderson et al., 2002 [12]; ¹² Hanna & Guthrie, 2000 [35]; ¹³ Hanna & Guthrie, 2000 [36]; ¹⁴ Hanna & Guthrie, 2001 [37]; ¹⁵ Hanna & Guthrie, 2003 [20]; ¹⁶ La Greca et al., 1990 [14]; ¹⁷ Gowers et al., 1995 [41]; ¹⁸ Burroughs et al., 1997 [17]; ¹⁹ Beresford & Sloper, 2003 [58]; ²⁰ Hay et al., 2004 [59]; ²¹ Williams et al., 1998 [60]; ²² Kyngas, 2000 [61]; ²³ Thomas et al., 1997 [62]; ²⁴ Gowers et al.,1995 [41]; ²⁵ Wysocki et al., 1992 [45]; ²⁶ Ott et al., 2000 [63].

Investigations specifically designed for an adolescent population have measured developmental changes in many ways. Within the model, these developmental changes are summarised into four areas: biological, psychological, cognitive and social. The literature is consistent in reporting that these variables have an impact on that individual's relationships across a range of contexts. For adolescents with diabetes it is proposed that as well as the generic lifestyle contexts of family and peer relationships, their relationships also extend to those health care providers with whom they have regular contact. In adolescence a trading of dependency occurs, switching from parents to peers [64] as the young person attributes greater importance to their peer influence [65]. Parental involvement in doctor-adolescent encounters can become problematic and adolescents are reluctant to communicate self care difficulties [58].

Responsibility for diabetic care increases with adolescent development in line with other adolescent activities, as does the concordance between the adult and child perspectives on the assumption of this responsibility. Over this time there is a close relationship between adolescent autonomy, parental involvement and family functioning, often assessed by way of diabetes-related conflict [12,33]. The adolescent's sense of increased autonomy can lead to substantial diabetes related conflict if this does not resonate with the parent's attributions of their child's autonomy, and their involvement fails to decrease over time. However, a degree of parental involvement remains a necessity, and, irrespective of the

child's age, it is the mothers who maintain this responsibility, demonstrating a good affinity to their child's perceptions about responsibility.

Appropriate sharing of the self-care responsibilities requires good communication between both parties as well as an understanding of the individual's process regarding the illness and its demands. Accepting and carrying out the range of self-care behaviours advocated in diabetes management carries a significant burden of responsibility. The process of assuming responsibility can be seen to be determined by a series of intrapersonal as well as interpersonal factors, which includes the individual's perceptions of the benefits and barriers to assuming responsibility [35], as well as their self-efficacy beliefs [66], illness representations [67] and sense of control over their illness [21]. For example, adolescents in a later stage of development, have a good factual knowledge of diabetes which relates to a perceived sense of control over potential outcomes and better adherence to their diabetes self-care [21]. Similarly, though not addressed in any of the literature reviewed for this paper, psychological problems can have a negative influence on metabolic control or adherence. Current opinion suggests that psychological difficulties can be viewed as markers of maladjustment to the disease, such as the inefficacy of coping strategies or learned helplessness, rather than as a direct consequence [54]. Such difficulties may also arise independently but interact with diabetes and its ramifications [68].

Good metabolic control and adherence is demonstrated in families with appropriate sharing of diabetes self-care responsibility, characterised by continued parental involvement facilitating knowledge and treatment adherence [14]. Adolescents in good control describe their family members as committed, helpful and supportive, and report good cohesion and less conflict within the family [69]. The literature suggests that even as these young people develop, they still want help, but that their acceptance of this help is influenced by their perceived need for help, and the kind of support offered [70]. Little is known of the intricacies of the support provided by other parties, such as health professionals or peers.

The model posited receives further support from a qualitative study identifying communication, reciprocal support between young people and professionals, and an individualistic as opposed to egalitarian family structure, as the main factors influencing metabolic control [71]. The consideration of developmental influences, family factors, diabetes ownership and both child and parent influences are also flagged in the clinical literature as important practical issues for assessing the readiness for the transfer of responsibility [13].

1.7 Methodological limitations

With regard to basic study design issues, cross sectional studies represent the majority of those presented in this review. Whilst such approaches demonstrate

useful associations between variables, they cannot determine the direction of these relationships. The lack of a control group is also of note, with only two studies [15,41] choosing such groups, and therefore being able to identify characteristics specific to a diabetic population, aside from those associated with other chronic diseases. A further methodological issue is sample size. Of the fourteen studies considered in this review, the largest study had a sample of 121 and most had samples of less than 80.

Another important issue concerns the characteristics of the sample studied. The variables of age and duration of diabetes are of note since there is frequently a negative correlation between metabolic control and age or diabetes duration [73-74]. Some studies addressed this issue by controlling for these variables in multivariate analyses [14,19,42] and this underscores the importance of sophisticated statistical techniques to address the interrelatedness of certain variables. Further, at least two of the studies reported that many of their participants had poor metabolic status [12,41], failing to reach recommended levels. This compromises the validity of this measurement and the opportunity for generalizing results.

Self selection bias is a key feature in research utilising interview and questionnaire methods. For example, in a comparison of adolescents with type 1, those who participated in research demonstrated significantly better adherence than non participants [74]. Also, self report data can be misleading.

Mothers can be very critical informants [15] and parent-child reports can be especially sensitive to familial conflict. Self report findings are also limited by the families own insights into their functioning, the accuracy of their reporting [75-76], and what they are prepared to disclose [41].

The measurement of the constructs outlined in this review is problematic. As noted previously, the term responsibility comprises a variety of characteristics and behaviours and is generally used to indicate an individual's undertaking and completion of given tasks. So a study that examines parental involvement with just one aspect of the diabetic regimen [21,41], may obtain a very different picture from one which assesses it across a range of health behaviours [14].

The same is true for singular adolescent report of autonomy [20], in comparison to a measure completed by both parent and adolescent [19,42]. Further, a measurement which includes some scope for the execution of a given task [20], provides distinctly different information from one which makes no reference to activity [19].

A final note refers to the number of instruments used to assess diabetes responsibility. Researchers should utilise instruments with proven validity and reliability such as the DFRQ, and develop instruments to address the narrowness of the focus on responsibility.

1.8 Implications for practice and research

The findings highlight the importance of ongoing family communication and emphasize the need for health professionals to be mindful that responsibility for self-care is likely to be a central theme, modulating the relationship between the developmental changes of adolescence and positive health.

Lifestyle factors such as family and peer relationships are significant in facilitating the adolescent's development and consequent autonomy for self-care, but these factors will also impact on the level of parental involvement. Traditionally, parental involvement reduces considerably over the course of adolescence, with some researchers estimating that participation within some aspects virtually ceases at the age of 15 [21]. Clinically this runs contrary to the adolescent's needs. Whilst few intervention studies have investigated the balance of self-care responsibility between parent and child, interventions designed to increase parental involvement or supervision, have been beneficial in decreasing non-compliance [77] as well as improving metabolic control and family conflict [33].

Motivation is an area of psychology with specific relevance to the issue of adherence to behavioural change. If the individual is not motivated to take responsibility for his/her own self-care, difficulties will undoubtedly arise. Self-efficacy contributes to motivation in several ways by shaping goals and

aspirations, determining effort, and shaping expected outcomes. It is a good predictor of behaviour [78] and there is support within the diabetic literature for its association with adherence [79] and metabolic control [80]. Self-efficacy has also been found to mediate the relationship between responsibility and good adherence [63]. Given this, interventions focusing on fostering a sense of efficacy may be beneficial in increasing the responsibility assumed by the young person, and by virtue of that responsibility, their performance of self-care behaviours. Target setting of goals by either parents or professionals can be used, along with encouragement and social support, to facilitate goal attainment and consequent self-efficacy enhancement.

The literature reflects the need for adolescents to retain some parental involvement in order to assume appropriate responsibility for their self-care [42]. Providing support to adolescents is one way in which parents can be involved whilst relinquishing their control and promoting the adolescents' assumption of diabetes responsibility [37]. Supporting the young person in attaining autonomy may comprise conveying an understanding of their perspective, acknowledging feelings, and providing relevant information with choices. Guided by the work of Deci and Ryan [81], and focusing on promoting behaviour which is internally generated as a consequence of that person's own decisions and self initiation, Williams et al. [60] have demonstrated the success of autonomy support interventions for adults with type 2 diabetes. These results have been replicated across a range of adult

clinical populations, and provided account is given to developmental change, there is no reason why similar interventions cannot be applied with adolescents. Self determination theory [81] and interventions guided by this approach, complement self-efficacy theory [78] since they account for both the individual's motivation and the role of significant others in supporting this.

Further research is warranted with larger samples to examine the intricate relationships between individual, contextual and outcome variables.

Investigations are needed to clarify the basic findings presented in this review, as well as to further explore the role of the family in adolescent diabetes, with particular attention to the handover of responsibility during adolescence [41].

Longitudinal and controlled studies using multivariate models are indicated to study the long term sequelae of responsibility, including the consequences of early versus late self-care autonomy on outcomes such as treatment adherence and metabolic control [45].

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CHAPTER 2: PAPER 1

The role of self efficacy and social support in predicting self care adherence in adolescents with type 1 diabetes

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Chapter Two: Paper One

The role of self efficacy and social support in predicting self care adherence in adolescents with type 1 diabetes

2.1 Abstract

Objectives

The aim of this study was to investigate the constructs of self efficacy, parental and peer social support, and shared responsibility, and their relative contribution to the prediction of dietary self care in adolescents with type 1 diabetes.

Design

A cross sectional design was employed.

Methods

A total of 109 adolescents (48 in early adolescence (12-13); 61 in mid-late adolescence (14-18)) with type 1 diabetes, and their parent/s, completed a series of questionnaires concerning their / their child's diabetes management.

Results

Regression analyses indicated that high dietary self efficacy, and high social support from friends, predict self care. Responsibility was significant as an interactive term, acting as a catalyst for the other mechanisms to predict self care. The reported relationships could be seen to vary by age group, since no significant results were reported in the older adolescent group.

Conclusions

In support of previous research, it was found that dietary self efficacy is the most significant predictor of self care, and that the value of good shared family responsibility can be seen to buffer low levels of self efficacy and support whilst enabling higher levels. However, the effects of these predictor variables are moderated by age, and this highlights the discrepancies between adolescents at different stages of development. Capturing the factors of most significance in predicting self care over the course of adolescence is of key importance to the advancement of this field, and is proposed as a focus for future research.

2.2 Introduction

2.2.1 Diabetes in adolescence

Adolescents with type 1 diabetes are vulnerable to a wide range of problems, making them a group of significant clinical concern. The literature documents difficulties with life satisfaction (Donnelly et al., 1995), treatment adherence (Kavanagh et al., 1993) and metabolic control, (Howorka et al., 2000) and presents an elevated risk for a variety of psychological disorders, including depression and anxiety (Rubin & Peyrot, 2001). These difficulties can be partly attributed to hormonal reactions (Amiel et al., 1986), but there is also evidence to suggest that this period is characterised by reduced self management (Johnson et al., 1992). Indeed, for adolescents experiencing a series of social, psychological, emotional, and physiological changes (Kyngas, 2000) self-management is difficult and both adherence and metabolic control often decline during this period.

2.2.2 Self Efficacy

Self-efficacy is a “judgement of one’s ability to organise and execute given types of performance” (Bandura, 1997). The development of self-efficacy beliefs is both socially and psychologically mediated. It incorporates direct mastery, vicarious experiences, social mediation by significant others, and both the changes and interpretation of physiological states and emotions. Self-efficacy contributes to

motivation in several ways, shaping goals and aspirations, determining effort, and influencing the individuals expected outcomes. These beliefs are not global, nor generalisable, and need to be framed in contextually representative frameworks to reflect perceived efficacy for a specified behaviour (Earley & Lituchy, 1991).

The self-efficacy approach is valuable within health as it helps explain the efficacy, motivation, and behavioural variation observed in individuals faced with similar situations when the same means for success are available (Bandura, 1997). People who perceive themselves as highly efficacious will expect favourable outcomes, while those with less confidence in their capabilities will anticipate negative outcomes. In chronic physical illness, individuals of high perceived efficacy are less stressed and depressed by their condition, and use better coping strategies than those of low perceived efficacy (Oliofoff et al., 1989).

As self-efficacy beliefs effect motivation, affect, and an ability to continue toward a goal in the face of setbacks, they are highly applicable to the complex behaviours of diabetes self-management. In adults, self efficacy has been associated with adherence across a range of self care behaviours including diet, exercise, blood glucose testing and insulin administration (Senecal et al., 2000; Williams & Bond, 2002). Higher self-efficacy scores are associated with higher self-rated adherence, and an increased sense of empowerment and treatment satisfaction (Howorka et al., 2000). Self efficacy can predict diet and exercise adherence even after controlling for past levels of adherence, metabolic control, and a number of demographic

variables (Kavanagh et al., 1993). Self efficacy is also a good predictor of metabolic control although this may be mediated by self-care (Johnston-Brooks et al., 2002) or perceived efficacy of treatment to control diabetes (Skinner & Hampson, 1998).

The literature examining the effects of self efficacy for children and adolescent's with type 1 diabetes supports the association between self efficacy and self care adherence (Grossman et al., 1987; Griva et al., 2000) and has found self efficacy to mediate the relationship between responsibility and adherence (Ott et al., 2000).

2.2.3 Social Support from family

Parents have a crucial role to play in the adjustment of adolescents in both general self-care and dietary self-care. (Burroughs et al., 1997; Goodall & Halford, 1991; Wysocki, 1993). Hanson, Hengeller & Burghen (1987) have found parental support, and it's interaction with age, to be directly linked with adherence, consistent with the developmental transitions that accompany adolescence. Families reporting good cohesion, parents who offer positive and supportive relations, open, and empathic communication, and those who encourage their children to take charge of their diabetes, have children who exhibit better metabolic control and psychological wellbeing (Evans & Hughes, 1987; Wysocki et al., 1992). Conversely, unsupportive family behaviours, characterised by conflict, criticism, distrust, and an indifferent attitude to the young person's diabetes management are associated with poor control (Anderson et al., 1981; Hauser et al., 1990).

The use of social support interventions within the family have been linked with an improvement in self care adherence (Anderson et al., 1999) as well as a reduction in familial conflict. Young people still want parental help, but the reception of this guidance depends on varying degrees of directness and the perceived need for help (Hanna & Guthrie, 2001). There is a danger that the young person's development of autonomy may be at risk in families where parents have a high level of involvement in the diabetes management (Evans & Hughes, 1987) consequently reciprocity and cooperation are encouraged.

2.2.4 Responsibility

Adolescents assume increasing responsibility for their diabetes self care with age (Anderson et al., 1990) but this is typically underestimated by the parents (Ott et al., 2000). Research indicates that parents should be involved in the care of the adolescent with diabetes whilst at the same time permitting the development of autonomy so he/she can do it alone (Wysocki et al., 1992). The need for continued collaboration between parent and child is highlighted by the finding that children assuming more responsibility for self care are in poorer diabetic control (La Greca et al., 1990).

2.2.5 Social Support from friends

The perception of diabetes related peer support increases along with the developmental changes of adolescence (Shroff Pendley et al., 2002). Friendship is an important vehicle for psychological development. For the adolescent with diabetes, friends and peers are able to provide emotional support, sensitivity and companionship (La Greca et al., 1995) in addition to practical support for self management. This support has been associated with a sense of well-being in adolescents with chronic illness (La Greca, 1990).

Friends can serve to help some aspects of the regimen yet hinder others (Schlundt et al., 1994). Whilst some studies have found friend support to be related to psychological adaptation (Varni et al., 1989), adherence (La Greca et al., 1995) and metabolic control (Skinner et al., 1996), the research is equivocal and others have not found these associations. For example, Thomas, Peterson, & Goldstein (1997) report that despite improved problem solving abilities in response to social situations, adolescents with Type 1 Diabetes are more likely to choose behaviours that are less regimen adherent, opting for actions consistent with peer desires. Conversely, adolescents may perceive their friends as being helpful with respect to their diabetes regime, but this may be limited by the availability of their friends and both the predictability and specificity of the support offered (Shroff Pendley et al., 2002).

2.2.6 Aims

The primary objective of this study was to examine whether the constructs of parental and peer social support add significant variance, over and above dietary self efficacy, to the prediction of dietary self care in adolescents with type 1 diabetes.

Based on the literature, the following hypotheses are put forward:

- 1) Social support (family and friends) will explain additional variance in self-reported dietary self-care, over and above the amount of variance explained by dietary self efficacy.
- 2) The effects of dietary self efficacy and social support will interact with shared family responsibility in determining the relationship with self care.

In keeping with current recommended research priorities, these analyses will be done separately to reflect the developmental stages of adolescence; early (ages 12-13) and middle-late (14-18).

2.3 Method

Ethical approval for this study was obtained from Coventry University (Appendix 1) and the Thames Valley Multi-centre Research Ethics Committee (Appendix 2). This study was part of a larger longitudinal study. This report represents the first phase of data collection.

2.3.1 Participants

The sample consisted of 245 young people who were registered at one of five paediatric diabetes outpatient clinics at five regional hospitals. Inclusion criteria required that individuals were aged between 12-18 years who had been diagnosed with type 1 diabetes for a minimum of 6 months. It was necessary for all participants to be able to read and speak English, as all measures included in this study had only been validated with an English speaking population. Young people with known learning disabilities, or those unable to read and / or speak fluent English were excluded from the research.

Of the 245 young people and their parents contacted to participate in the study, 127 adolescent-parent pairs agreed to participate. The final sample consisted of 109 (49 boys, 60 girls) participants, with completed data sets from both parent and child. The characteristics of the sample are summarized in table 2.1.

Table 2.1 – Table summarizing demographics of sample

Demographics	Early Adolescents (12-13yrs)					Mid-Late Adolescents (14-18yrs)				
	N = 48					N = 61				
	Lower Q'tile	Median	Upper Q'tile	Mean	S.D	Lower Q'tile	Median	Upper Q'tile	Mean	S.D
Duration since diagnosis (months)	24.00	38.00	81.00	50.67	5.26	29.00	60.00	108.00	79.72	14.53
BMI	18.08	20.70	23.10	20.81	0.49	20.80	22.55	24.6	23.20	0.47
Hospitalisations (Incidence in last 6 months)	0.00	0.00	0.75	0.29	0.08	0.00	0.00	1.00	0.61	0.16
Exercise (hours per week)	2.25	5.00	9.75	6.56	0.72	2.50	5.00	10.00	7.31	0.93
Treatment complexity	2.00	4.00	5.00	3.70	0.26	2.00	3.00	4.88	3.53	0.23

Using HbA1c as a measure of diabetes control, reflecting the average blood glucose level over the preceding 3 months, 96% of the younger sample, and 98.4% of the older sample were outside of the target range (< 7.5) recommended by the European Diabetes Policy Group (1988). 25% of the younger sample and 28% of the older sample had also received hospitalisation for their diabetes in the preceding 6 months. BMI criteria, recommended by the World Health Organisation (WHO, 1998) indicated that 57% (41% younger group, 67% older group) of the sample were classed as healthy weight, 27% (43% younger group, 14% older group) were underweight, and 16% (9% younger group, 19% older group) were overweight. The alcohol use of the young people was considerably less than that of their peers when

compared with age appropriate norms (Boreham & Shaw, 2001; Office for National Statistics, 2004). 14% of the younger group, and 25% of the older group had consumed an alcoholic drink in the past week.

2.3.2. Procedure

Potential participants were identified at each site, and letters of invitation (Appendix 3), including information leaflets and consent forms (one for the child/adolescent (Appendices 4, 5, 6, & 7) and one for the parent/guardian (Appendix 8 & 9)), were either sent to the potential participant's home addresses, or handed to them at their routine clinic out-patient appointment or home visit.

All individuals who agreed to participate, and parents of all those under 16 years of age, then completed an informed consent form. For those participants under the age of 16, parents or guardians were required to counter sign the consent form stating their agreement for the adolescent to participate. The consent form allowed participants to acknowledge the preferred option for completion of the questionnaires which included: (a) questionnaire booklets to be sent to their home address and returned in a pre-paid envelope; (b) contact to be made by telephone to arrange a mutually convenient time for a home visit for questionnaire completion; or (c) that they can be approached at their next out-patient clinic/ home visit and given the questionnaires for completion. The majority of participants opted to complete the questionnaires at their next out-patient appointment.

After explanation of the instructions, participants were then asked to complete the booklet in their own time. For those participants who opted to complete the questionnaires at clinic, they either returned them to the researcher prior to leaving the clinic, or returned them by post. A similar procedure was followed for those who opted to complete the questionnaires at home.

2.3.3. Measures

General Information (Appendix 10 & 11)

Adolescents and their parents provided information on general demographics including alcohol use, diabetic regimen and illness-related questions including the duration of illness, treatment complexity, height and weight measurements, and the number of hospitalizations in the previous 6 months. The diabetic regimen information was translated into a measure of treatment complexity, a figure indicating the recommended number of daily diabetes care activities completed.

Dietary Self Efficacy (Appendix 12 & 13)

Adolescents and parents rated on a 26-item scale their confidence in their/their child's ability to follow recommended dietary self care activities on a regular basis, given common barriers to self care. The barriers were based on the work of Glasgow et al., (1986) and Schlundt et al., (1994).

For this study, Cronbach's alpha was 0.96 (child) and 0.97 (parent).

Diabetes Social Support Questionnaire – Family Version – Modified (DSSQ-Family) (La Greca & Bearman, 2002) (Appendix 14)

The adolescents completed the DSSQ-Family, a 20 item scale developed as a measure of family member's supportive behaviour for adolescents with type 1 diabetes. For this study, only the individual measure of perceived support, based on the frequency adjusted for the ratings of supportiveness, was used. This scale has been modified for inclusion within this study by selecting only those items applicable to dietary self-care.

For this study, Cronbach's alpha was 0.89 (frequency measure) and 0.94 (individual measure).

Diabetes Social Support Questionnaire – Friends Version – Modified (DSSQ-Friends) (Bearman & La Greca, 2002) (Appendix 15)

The adolescents completed the DSSQ-Friends, a 13-item scale developed as a measure of friends' supportive behaviour for adolescents with type 1 diabetes. As for the family version of this scale, only the individual measure of perceived support was used. This scale has been modified for inclusion within this study by selecting only those items applicable to dietary self-care.

For this study, Cronbach's alpha was 0.92 (frequency measure) and 0.92 (individual measure).

PAID (Problem Areas In Diabetes) (Appendices 16 & 17)

Adolescents and their parents completed this measure. The original scale was designed to assess emotional functioning in adults with diabetes (Polonsky et al., 1995) and a long form is available for assessment with adolescents and their main care giver. For this study the scale has been modified. The wording of the adult short form of the scale has been used and enhanced by adding the script for questionnaire completion offered in the long form adolescent scale.

For this study the Cronbach's alpha was 0.92 (child) and 0.94 (parents).

Glycosylated haemoglobin (HbA1c)

HbA1c is a measure of diabetes control reflecting average blood glucose over the preceding 3 months (Marshall et al., 2000). Metabolic control was determined by averaging the last obtained readings documented in the patient's medical records.

Summary of Diabetes Self Care Activities Scale (SDSCA) (Toobert & Glasgow, 1994) – Adapted (Appendices 18 & 19)

Adolescents and their parents completed this adapted measure. The original 12-item self-report instrument assesses areas of diabetes self-management: diet, exercise, blood glucose control, and insulin injecting over the past 7 days and has been adapted by Urquhart-Law (2002) for UK readability. For this study, only 7 questions applicable to diet and insulin injecting were used to obtain a composite score for these regimens.

Cronbach coefficient alphas were 0.51 (child) and 0.48 (parent) for diet, and 0.54 (child) and 0.64 (parent) for blood glucose testing. Whilst the reliability statistics for this measure are relatively poor, it is the most widely used, and has been employed with similar reported internal consistencies in other studies (Skinner et al., 2000; Urquhart-Law, 2002).

Diabetes Family Responsibility Questionnaire (DFRQ) (Anderson et al., 1990) (Appendix 20)

This 17-item questionnaire was developed to assess the sharing of diabetic responsibilities between mothers and their diabetic children. Both adolescents and their parents completed this scale which provides a total measure of the young person's assumed responsibilities, as well as a measure of the level of agreement

between parent and child in sharing the responsibilities for the young person's diabetes treatment tasks.

This scale has been demonstrated to have high internal consistency and concurrent validity (Anderson et al., 1990). For this study, Chronbach's alpha was 0.78 (child) and 0.84 (parent).

2.4 Results

2.4.1. Descriptive findings

Both groups of adolescents (early and middle-late) reported relatively high self efficacy for implementing their dietary regime and seeking social support. They reported minor problems living with and managing their diabetes, but tended to assume responsibility for the majority of their self care demands. Overall, the young people reported being fairly adherent to their dietary treatment regimen (see Table 2.2 for means).

The two age groups did not differ significantly in terms of metabolic control, representation of males and females, and duration of diabetes, although across the whole sample, age was positively correlated with disease duration ($r = 0.233$, $p < 0.05$). Level of perceived family support differed significantly between the groups with the older children reporting less social support from their families $t(104) =$

2.237, $p < 0.05$. The level of perceived support from friends was also reduced for the older group although this was clinically, as opposed to statistically significant, $t(104) = 1.874$, $p = 0.065$. As expected, the older children assumed greater responsibility for the tasks of their diabetes treatment as measured by the total DFRQ for both mothers, $t(105) = -3.072$, $p < 0.01$, and children $t(105) = -2.104$, $p < 0.01$, than their younger counterparts. There were no significant differences in level of shared family responsibility between the two groups although the level of containment was lower for the older groups, such that more of the diabetes management tasks could be explained as “no one takes responsibility for that”.

Matched sample t tests revealed no differences between the adolescents and their parents, on the PAID or the measure of dietary self efficacy, but did reveal differences on the dietary composite of the SDSCA, a measure of adherence, and the DFRQ, the measure of responsibility for treatment. These differences were observed for both age groups, early and middle-late adolescents respectively. The parents perceived their children to have greater adherence to their dietary self care, $t(46) = -2.958$, $p < 0.01$; $t(59) = -3.874$, $p < 0.001$ and did not agree that the adolescents were responsible for as many treatment tasks as the adolescent perceived, $t(46) = 3.007$, $p < 0.01$; $t(58) = 3.011$, $p < 0.005$.

Table 2.2 Table providing a comparison of parent and child ratings, across age groups, for the main study variables.

Variable	Parent ratings		Child ratings		Possible range
	Mean	SD	Mean	SD	
Early Adolescence (n=48)					
Dietary self efficacy	185.06	54.24	182.29	56.30	0 - 260
PAID	47.44	18.09	42.19	18.56	20 - 120
DFRQ child responsibility	11.26	2.58	12.57	2.60	0 – 17
Dietary self care	14.67	2.27	13.64	2.89	0 – 20
Perceived social support–family	-	-	163.24	86.06	-100 - 300
Perceived social support-friends	-	-	63.13	56.05	-65 - 195
Mid-Late adolescence (n=61)					
Dietary self efficacy	179.09	47.16	173.30	47.35	0 – 260
PAID	47.87	19.40	43.50	17.30	20 – 120
DFRQ child responsibility	12.80	2.63	13.65	2.64	0 – 17
Dietary self care	14.42	2.41	13.13	2.92	0 - 20
Perceived social support–family	-	-	128.93	66.69	-100 - 300
Perceived social support-friends	-	-	44.77	40.01	-65 - 195

2.4.2 Prediction of dietary self care

The relationships between the dependent and independent variables involved in the multiple regression analysis were checked and the analysis was found to meet the four associated assumptions. Hierarchical multiple regression analyses were therefore performed. This technique was utilised so that the unique variance of each

predictor variable could be determined, while controlling for the effects of the other variables in the model. The unique variance is defined as the proportion of R^2 that is attributed to the predictor variables as if it was entered last in the model. Separate models were generated to predict dietary self care for the two age groups.

The relationship between self-reported dietary self care and dietary self efficacy, social support (family) and social support (friends) was evaluated using a blocked ordinal least squares regression analysis. The regression was formed using two blocks of variables. In the first block, the covariate, dietary self efficacy was entered into the regression. The primary variables (social support family and social support friends) were entered in the second block alongside responsibility. All the responsibility interactions were included in this block to allow the effect of responsibility on dietary self care to differ by the predictor variables.

2.4.2.1 Early adolescence

Using the enter method as detailed above a significant model emerged. The first block resulted in a model $R^2 = 0.358$ ($F_{1,43} = 25.566$; $p < 0.0005$) with a positive beta coefficient for dietary self efficacy of $\beta = 0.611$ ($t = 5.127$, $p < 0.0005$). The second block resulted in a model $R^2 = 0.520$ ($F_{6,37} = 7.818$; $p < 0.0005$). The change in R^2 resulting from the addition of the variables measuring social support and their interactions with responsibility was $R^2 = 0.224$ ($F_{6,37} = 3.421$; $p = 0.009$). Accordingly, the variables measuring social support and their interactions with

shared family responsibility did account for additional variability over and above that explained by dietary self efficacy (Hypothesis 1). Variables are shown below in table 2.3.

Table 2.3 – Results of hierarchical multiple regression with early adolescent group

	Unstandardized Coefficients		Standardized Coefficients	t	p
	B	Std.Error	Beta		
(Constant)	13.480	0.316		42.683	0.0005
Dietary self efficacy	1.823	0.356	0.690	5.127	0.0005
DFRQ Family sharing responsibility	-0.161	0.328	-0.060	-0.491	0.627
Dietary self efficacy*DFRQ Family sharing	-1.053	0.455	-0.503	-2.316	0.026
Social Support – Family	-0.445	0.390	-0.171	-1.141	0.261
Social Support – Friends	0.959	0.376	0.386	2.553	0.015
Social Support – Family*DFRQ Family sharing	1.311	0.428	0.762	3.059	0.004
Social Support – Friends*DFRQ Family sharing	-1.091	0.445	-0.536	-2.451	0.019

For dietary self care, dietary self efficacy is the most significant predictor of the child’s scores. When controlling for dietary self efficacy ($\beta = 0.690$), family social support ($\beta = -0.171$) did not significantly predict the child’s dietary self care but friend social support was significant ($\beta = 0.386$). The effect of familial sharing of

diabetes related responsibility on self care was not significant as an individual variable ($\beta = -0.06$) but its interactions with the other variables were significant such that the effect of family sharing of responsibility was dependent upon dietary self efficacy ($\beta = -0.503$), family social support ($\beta = 0.762$) and friend social support ($\beta = -0.536$) (Hypothesis 2). The final model explained 52% of the variance of dietary self care, and indicated that higher levels of self efficacy and social support from friends, combined with the interaction of family sharing of responsibility with dietary self efficacy, family support, and friend support, significantly contribute to better adherence to dietary self care.

Following the method of Aitken and West (1991), the interactions were plotted in order to understand their relative meanings. The presence of the interactions equivalently means that the effect of the predictors: dietary self efficacy, social support from friends, and social support from family, is conditional on the level of shared family responsibility, of which high values suggest a good containment of the tasks of diabetes management within the family (i.e. few tasks are being overlooked).

2.4.2.2 Mid-Late adolescence

Using the same enter method as detailed above no significant model emerged within the older age group. The first block resulted in a model $R^2 = 0.046$ ($F_{1,56} = 3.735$; $p = 0.058$) with a positive beta coefficient for dietary self efficacy of $\beta = 0.250$

approached significance ($t = 1.932, p = 0.058$). The second block resulted in a model $R^2 = 0.025$ ($F_{6,50} = 1.205, p = 0.318$). The change in R^2 resulting from the addition of the variables measuring social support and their interactions with responsibility was $R^2 = 0.082$ ($F_{6,50} = 0.797; p = 0.577$). Accordingly, the variables measuring social support and their interactions with shared family responsibility did not account for any additional variability over and above that explained by dietary self efficacy (Hypothesis 1). Variables are shown below in table 2.4.

Table 2.4 - Results of hierarchical multiple regression with mid-late adolescent group

	Unstandardized Coefficients		Standardized Coefficients	T	p
	B	Std.Error	Beta		
(Constant)	13.456	0.415		32.421	0.0005
Dietary self efficacy	0.389	0.460	0.123	0.846	0.402
DFRQ Family sharing responsibility	0.779	0.470	0.246	1.656	0.104
Dietary self efficacy*DFRQ Family sharing	-0.218	0.525	-0.057	-0.415	0.680
Social Support – Family	0.448	0.514	0.133	0.872	0.387
Social Support – Friends	0.245	0.564	0.070	0.434	0.666
Social Support – Parental*DFRQ Family sharing	0.289	0.507	0.093	0.569	0.572
Social Support – Peers*DFRQ Family sharing	0.952	0.719	0.241	1.324	0.192

For the mid-late adolescents, none of the variables were significant in predicting the criterion variable (Hypothesis 2). No significant interactions were found between the independent variables and responsibility to predict dietary self care.

2.5 Discussion

Dietary self efficacy has been found to be a strong predictor of adolescent's adherence to their dietary self care. In the present study, using two age groups, social support from family and friends was examined to see if it made any additional contribution to the prediction of dietary self care. For the younger group, classified as those in early adolescence, high levels of self efficacy predict better dietary self care, and this dietary self care is further improved by better perceived support from friends, thus confirming hypothesis 1. To the author's knowledge, this is the first paper to report these findings, although the value of self efficacy (Griva et al., 2000) and social support from friends (La Greca et al., 1995) has previously been documented.

For the older group, and those adolescents in the mid-late stages of this developmental period, dietary self efficacy approached significance in predicting adherence to dietary self care but the social support variables made no additional contribution. Whilst the insignificance of dietary self efficacy is a surprising result, discordant with the current body of literature (e.g. Grossman, 1987), current studies

are equivocal in reporting the impact of perceived social support from both family and friends, as both supportive and unsupportive.

Analysing data separately for two distinct phases of adolescence is a method which has previously been employed by other researchers investigating type 1 diabetes (e.g. Hanna & Guthrie, 2001) and given the contrasting results, seems of particular value. In this study the effects of predictor variables on self care can be seen to be moderated by age. Increasing age is linked with reduced adherence (Jacobson et al., 1990), and a change in the reception of social support. Support from parents is seen as of less value whilst the value of that from friends increases (Furman & Buhrmester, 1992). With age, the adolescent is also required to manage increasing numbers of conflicting priorities. The lack of significant results in this group may simply indicate that the value of other factors, such as typical adolescent task pursuits are of better predictive power than traditional models of health behaviour. There is also the possibility that this group provided less reliable self reports for fear of negative consequences, or were less conscientious completing the measures.

Perhaps of greatest significance in this study is the finding that the impact of shared family responsibility is dependent upon the values of the other predictors. It was hypothesised that the effects of dietary self efficacy and social support from both family and friends, would interact with shared family responsibility in determining their relationship with self care. For the younger group, the effect of this family responsibility was not significant individually, but highly significant as an

interaction term. This shared responsibility can be interpreted as a catalyst for other mechanisms to predict dietary self care. For dietary self efficacy, the effect of responsibility on self care is higher when self efficacy is low and vice versa, such that the power of self efficacy in predicting self care increases as when the family sharing of responsibility is low. The same holds true for the effect of social support from both family and friends. Thus the effect of shared family responsibility on self care increases as social support decreases and the effect of this social support from friends increases as responsibility decreases.

The value of good shared family responsibility can be seen to buffer low levels of self efficacy and social support whilst enabling higher levels of these same variables. The results of this study enhance the findings of other studies which have established responsibility in a mediating role between self efficacy and adherence. In this study, for young adolescents, responsibility interacts with other variables to significantly predict self care. This is in keeping with literature on the role of responsibility and the importance of continued parental involvement for young people throughout the course of adolescence (Anderson et al., 2002).

The present study furthers the knowledge in the field of type 1 diabetes in the early stages of adolescence by demonstrating the factors significant in predicting good self care. It also highlights the role of shared family responsibility in modifying the effects of self efficacy, and social support from both family and friends. This paper highlights the discrepancies between adolescents at different stages of development

and the need to consider alternative models, over and above those traditionally associated with the prediction of health behaviours, to predict adherence to dietary self care in adolescence.

2.6 Methodological considerations

Any conclusions about the roles of dietary self efficacy, perceived social support and the interaction of shared family responsibility need to be considered within the confines of the present cross-sectional design. There is also the issue of sample bias. A substantial proportion (48%) of those who were approached to take part in the study declined and 14% of those who did consent failed to return their questionnaires. One possible explanation might be that these were individuals with low levels of adherence (Riekert & Drotar, 1999) who feared disclosure, or, along similar lines, that their unwillingness to participate in the study indicated a general pattern of non-compliance (Roberts & Wurtele, 1980).

Whilst the use of self report measures may limit the generalization of the findings it is the author's view that these effects are minimised, since support for the validity of many of the measures is provided by the agreement between the adolescents' and their parents' ratings. However, the instrument to measure dietary self care has poor reliability and this may well have impacted on the obtained results. Current dietary advice provided for young people with diabetes is less rigid than the ideal required for a high score on the self-care measure used, so the adherence levels reported may

not adequately represent the actual behaviours of these young people. Further, some of the test items referring to adherence to dietary self care seemed to be somewhat ambiguous which might have contributed to the outcome.

2.7 Treatment implications

The results of this study have important implications for facilitating effective self management for young people in the early stages of adolescence. Since dietary self efficacy was identified as the most significant predictor of dietary self care adherence in this group, interventions to increased the perceived self efficacy of these young people, such as mastery experience, social persuasion, social modelling (Bandura, 1997) and goal setting, may be used in families where dietary adherence is an issue of concern.

Given the value of shared family responsibility, highlighted by the results of this study, it is important to facilitate this in families of diabetics. Interventions to increase parental involvement or supervision have been beneficial across a range of health outcomes for diabetes (Anderson et al., 1999), and the value of overt discussion in communicating individual responsibility for the range of diabetes related tasks within the family is clear.

Group discrepancies across the period of adolescence highlight the need to target clinical and social interventions based on that young persons developmental stage

rather than classifying all adolescents the same. The complexity of adolescence can not be underestimated and no hard and fast rules can be applied (Burroughs et al., 1997).

2.8 Future research directions

Additional research is warranted with larger samples to further examine the relationships purported in this study. The use of longitudinal investigation to examine variability across time and the causal interplay between the variables reported would be of benefit. The current study is planned as phase 1 of a long term study. Future researchers may wish to consider qualitative methods, such as interviews or focus groups, in addition to the quantitative measures, to explore some of the other factors significant in predicting adherence to diabetes management, as well as the interactions between variables.

The measurement of the constructs is a concern given that many of the scales utilised with this population have been designed for adolescents as a whole group and do not consider the developmental stages within this period. Future research may focus on discerning scales specific to age ranges.

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CHAPTER 3: PAPER 2

The experience of living with type 1 diabetes: A comparison of female adolescents and their mother's perspectives – An Interpretative Phenomenological Analysis

This paper has been prepared for submission to Qualitative Health Research

(See Appendix 36 – Author Guidelines)

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Chapter Three: Paper Two

The experience of living with type 1 diabetes: A comparison of female adolescents and their mother's perspectives – An Interpretative Phenomenological Analysis

3.1 Abstract

Good control is important for minimising the potential for acute symptoms and long term consequences in type 1 diabetes. Achieving good diabetes control is difficult. Many young people, and their parents, have difficulties at some time, particularly during adolescence. This article is based on focus groups carried out with 4 adolescents and 3 of their parents. The views of adolescents with type 1 diabetes, relating to their condition, are explored, and contrasted with the perceptions of their parents.

This study highlights the perceptions of both the young people and their parents, and how each, in a different way, finds it difficult. Diabetes management was recognised as a shared process between parent and child, and for both groups, long term diabetes management and adolescent development was about juggling conflicting priorities. Four domains were identified; emotions, identifying with illness, support and long term management. The implications for clinical practice are discussed, and recommendations made for further research.

3.2 Introduction

Type 1 diabetes is a life-long condition in which the pancreas stops making insulin. Without insulin, the body is not able to use glucose for energy and in order to restore and maintain metabolic balance, the individual must inject insulin, follow a diet plan, exercise daily, and test blood sugar several times a day. The main aim of treatment for diabetes is to relieve the unpleasant symptoms of high and low blood glucose by maintaining 'near normal' blood glucose levels. Good diabetes control also greatly reduces the risk of diabetes complications which can affect the feet, eyes, kidneys and circulation. Control is not always easy to achieve though, and many young people, and their parents, have difficulties with this at one time or another (Diabetes UK, 2000).

Adolescence is a notably difficult time for the young person with type 1 diabetes, and many researchers have reported that diabetes self care and metabolic control are compromised during this period. The developmental demands of adolescence are often seen to conflict with the demands of the diabetes regimen. For example, the formation of personal identity, or self concept, is an important developmental task of adolescence (Erikson, 1984; Montemayor & Eisen, 1977) but research has highlighted how parental involvement, actively encouraged in the families of the young person with diabetes (Anderson et al., 1999), can conflict with the adolescent's developing sense of autonomy (Coupey & Cohen, 1984).

The literature relating to the experience of living with type 1 diabetes is scarce. Most literature on adolescents with type 1 diabetes has focused on quantitative investigations, with many studies investigating the effect of a given variable on health outcome, specifically adherence or metabolic control.

Schur, Gamsu, & Barley (1999), present a phenomenological study, exploring the experience of living with diabetes from the young person's point of view. Their findings show that much of the young person's experience is about managing their relationship with diabetes, and their efforts to manage the practical and emotional threats from the diabetes. For the young person developing a relationship with diabetes, they describe the shock of diabetes, learning to live with diabetes and finally seeking an optimal relationship with the diabetes. In learning to live with the illness, these young people developed a series of self-protective strategies to manage both the intrapersonal and interpersonal threats of the illness. The authors discuss the importance of coping strategies, such as the perception of control, and denial, as 'fundamental to how (the young person) is able to manage living and coping with diabetes'. The study highlights the development of a relationship between the young person and their diabetes, the progression of acceptance, and the role of parental involvement and sharing to facilitate these changes. The experience of difference is profound for the young people and suggestions are made for how services may help society acknowledge and manage the differences that comes from having diabetes.

The experience of parents has been largely overlooked but is considered in a qualitative study by Dashiff (1993). This study explores the parent's perceptions of the experience of diabetes in their adolescent daughters using content analysis on semistructured interviews. For these parents, whilst the child's diabetes was perceived to draw the family together it negatively affected spousal relations. A central process of the experience for parents was the suffering of emotional distress related to concerns about diabetes control.

Qualitative investigations have focused on the role of social support in diabetes. Olsen and Sutton (1998) studied the content and substance of relationships between adolescents with diabetes and their families and friends using a focus group methodology. Their study investigated how these relationships changed and developed over time, as well as how they interacted with formal support from health professionals. Broadly, they identified an increase in the complexity of the pressures which the older adolescent needs to deal with in order to manage their diabetes. Balancing diabetes within friendship and family networks became more complicated, and included dilemmas about how much that young person should reveal to their work colleagues, or a new partner, about their diabetes. These occurred during a time when there was a progressive withdrawal of both formal and informal support and could lead to feelings of insecurity and isolation.

The nature and meaning of the conflicts and supports for adolescents in the management of their diabetes, and specifically with their parents, has been a source

of another focus group investigation (Weinger et al., 2001). In this study, the researchers interviewed groups of adolescents between the ages of 13-15 years and gathered personal accounts. Three sources of conflict were identified: parental worry and intrusive behaviours such as nagging or asking too many questions, parent's lack of understanding and blaming behaviours, and parent's future concerns in conflict with the adolescent's focus on present concerns. There was minimal discussion of parental support but empathy for the demands of diabetes and reassurance about diabetes and normative functioning were mentioned in positive accounts.

Hanna and Guthrie's studies qualitative investigations have included the views of both the adolescent with type 1 diabetes and their parents, the parents accompanying views having been neglected in many of the previous studies. These studies have identified a series of benefits and barriers to the assumption of diabetes management (Hanna & Guthrie, 2000a; 2000b; 2001). For the adolescents, greater responsibility was associated with more confidence, freedom and the approval of others but they were concerned about the burden of responsibility. For the parents, adolescents diabetes self management evoked a relief from burden and feeling of confidence and pride in their child's abilities, however, they felt threatened by a loss of control, supervision, and the lack of barriers. A later study (2001) compared the views of parents and their adolescents on helpful and non helpful support, specific to the adolescent's assumption of responsibility for diabetes management. The same categories of support, directive guidance and tangible assistance, were described as

both helpful and non helpful, and the author's concluded that this was dependent on the degree of directness and the perceived need.

Aside from the Hanna and Guthrie articles, the literature has failed to integrate the views of both young people and their families. The involvement of both young person and parent is indicated and encouraged in successful diabetes management throughout adolescence (Weissberg-Benchell et al., 1995; Anderson et al., 1999), and given this, the experience of both parties is important in understanding their needs, and considering how these may be met. An exploration of both the adolescent's and their parents' perspective on living with diabetes is warranted.

3.3 Aims

The present investigation aimed to explore and contrast the views of adolescents with type 1 diabetes, and their parents, specifically relating to the perceptions and understanding of their illness.

3.4 Method

By means of focus group interviews, we asked participants to describe their motivations for self care and the role of social support. Data collected was analysed using thematic analysis in the process laid out for Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003).

3.4.1 Participants

Ethical approval was obtained from Coventry University (Appendix 21) and the local NHS Primary Care Trust (Appendix 22).

Participants were recruited through the Diabetic Specialist Nurses at a Children's Outpatient department. A total of 30 potential participants were given a letter of invitation and an information leaflet explaining the nature of the study (Appendices 23 and 24). The invitation sheet gave details of the purpose of the discussion, explained how the focus groups would operate, and stressed the voluntary nature of the group.

Participants were young people aged between 12-16 years with a diagnosis of type 1 diabetes, and their parents. In order to take part in the study, participants had to fulfil the following criteria: they needed to have type 1 diabetes of at least 6 months duration, be aged between 12 and 16 years, and be able to converse in English.

All of the 14 adolescent-parent pairings who expressed an interest in the study were invited to take part in a Focus Group, and of these, 7 pairings agreed to attend. Two focus groups were scheduled, one each for the parents and the adolescents. Letters confirming the invitation and session arrangements were sent to the participants and a telephone reminder was provided the day before the focus group was due to take place. Of these 7 adolescent-pairings, only 4 adolescents and 3 parents attended the groups. Written consent was obtained from each participant (Appendix 25)

3.4.2 Sample characteristics

All of the young people who participated were female and 14 years of age. The young people had been diagnosed with type 1 diabetes for an average of 28 months, with a range of 9 months to 4½ years. All of the parents who took part were mothers.

3.4.3 Procedure

The purpose of using focus groups in this study was to obtain personal accounts from both adolescents, and their parents, of their motivation for self care (or their motivation for supporting their child with self care) and the role of support in this process. Focus groups were chosen as the appropriate method for exploring these issues since they have proved to be a particularly popular and successful qualitative methodology in health research (Pope & Mays, 1995; Murphy et al., 1992), and, more specifically, have previously been used to good effect in other qualitative studies of type 1 diabetes in adolescence (e.g. Weinger et al., 2001). Focus group interviews are well suited to exploring potentially difficult topics, in that they are open and flexible (Morgan, 1998), offer the opportunity to collect data from group interactions, and further, that this group context may serve to facilitate personal disclosures (Wilkinson, 2003). Some researchers have suggested that this form of research provides some quality controls on data collection in that participants tend to

provide checks on each others responses (Patton, 1990), however others argue that this same process may inhibit contributions from shy participants.

Focus groups were held in the evening, at a local hospital, to ensure a convenient location for all participants. No payment was made for travel or participation. The parental focus group took place immediately after the adolescent group and during this time the Diabetic Specialist Nurse took the children out for dinner.

The focus group leader used a prepared set of open-ended questions to guide the 70 minute sessions, with questions designed specifically for either the parent or adolescent group (Appendices 26 and 27). Young people and their parents were asked to describe their experience of managing their diabetes, and specifically about what motivated them and the impact of social support. The focus groups were tape-recorded and later transcribed verbatim. Additional consent was obtained for the audio recording (Appendices 28 and 29). An observer was also present to take additional notes during the sessions. In consideration of the matters discussed above, and in an attempt to ensure the focus group interview was representative of each participant's experience, efforts were made to elicit responses from all participants. The researcher used qualitative techniques suggested for use within focus group interviews as suggested by Krueger (2000) and Morgan (1998).

3.4.4 Analysis

The transcripts were analysed by the author using thematic analysis employing the process laid out for use by interpretative phenomenology. Interpretative Phenomenological Analysis (IPA) was chosen to analyse the data because it is primarily concerned with obtaining an ‘insider’s perspective’ (Conrad, 1987), through finding out how individuals perceive the particular situations they are facing, and how they are making sense of their experiences. This approach is valuable to the particular area of investigation as it does not seek out an objective statement of how young people and their parents understand and experience diabetes self management, but explores their personal account. At the same time, IPA recognises that the research process is a dynamic process in that attempts to access the participant’s personal world is complicated by the researchers own conceptions. In this way, the researcher engages in a process of interpretative activity (Smith, 1996).

Details of each stage of the analysis process are summarised in Table 3.1

Table 3.1

Stage 1	<p>Reducing the raw information (Appendix 30)</p> <p>Focus group interview transcript read a number of times and preliminary notes made of what is interesting or significant within the respondents discourse.</p>
Stage 2	<p>Document emerging themes (Appendix 30)</p> <p>Notes transformed into phrases to capture the quality of what is found in the text, whilst remaining grounded in the actual text.</p>
Stage 3	<p>Looking for connections (Appendix 31)</p> <p>Connected themes clustered together. Transcripts were checked to make sure the connections concurred with the primary source material and the actual words of the respondent. Directories of participant's phrases created that support the related themes.</p>
Stage 4	<p>A table of themes (Appendix 32)</p> <p>Themes ordered coherently and a title or master theme assigned to each of the clusters. These were reviewed and worked upon with the qualitative research collective. Themes with poor fit and inadequate evidence dropped.</p>
Stage 5	<p>Master list of themes (Appendix 33)</p> <p>Consolidated list of master themes produced.</p>
Stage 6	<p>Writing up</p> <p>Themes converted into narrative account. For anonymity, names of participants have been replaced with fictitious ones.</p>

The evolving guidelines for the publication of qualitative research suggested by Elliot et al. (1999) have been used as a lead to good practice. In line with this, independent audits for both focus group interviews were carried out by a qualitative research collective (consisting of four colleagues/qualitative analysts external to the study) to verify the validity and reliability of the analysis. Using a paper trail linking the text to the themes, the qualitative research collective checked the logical progression through stages of analysis, validated the authors reading and interpretation, and checked the stages to ensure the final report was credible in terms of the data collection. As a further quality control, the group themes were sent back to the original participants. One of the adolescent participants has since returned information confirming that the themes identified resonated with her own personal experiences. Unfortunately, up to this time, replies have not been received from any of the other participants.

3.5 Results and discussion

The analysis of the transcripts from the adolescent and the parent groups were undertaken separately since any attempt at combining would breach the homogeneity of the two groups, and result in a loss of the richness within the data.

To some extent, the management of diabetes in adolescence is a shared experience between parent and child, and there are substantial similarities in the master and sub-themes which emerge from the two groups (table 3.2 and 3.3). Considering this, and

for the purposes of discussion and comparison, the master and sub-themes which emerged from each of the focus groups interviews have been subsumed into four domains (see table 3.4) – emotions, identifying with illness, support and long term management. This is the author’s interpretation of the combined information conveyed through the two focus groups.

Table 3.2 - A table of the master and sub themes from the child focus group

Master themes	Sub-themes
Emotions	Isolation
	Fear
	Guilt
	Anger
Identity	Being a teenager
	Having diabetes
	Conflict in identity
Support	Parental support
	Peer support
Integration	Acceptance
	Responsibility

Table 3.3 – A table of the master and sub themes from the parent focus group

Main themes	Sub-themes
Emotions	Guilt
	Anger
	Anxiety
	Burdened
Identity as Parent	Parenting a teenager
	Parenting a child with diabetes
	Conflict in parental role
Role of others	Peer support
	Wider awareness
Balance	Good enough
	Sharing responsibility

Table 3.4 – A table of the domains shared by the two groups

Domain	Master theme	Sub-themes
Emotions	Emotions (Adolescent)	Isolation
		Fear
		Guilt
		Anger
	Emotions (Parent)	Guilt
		Anger
		Anxiety
		Burdened
Identifying with illness	Identity (Adolescent)	Being a teenager
		Having diabetes
		Conflict in identity
	Identity as parent (Parent)	Parenting a teenager
		Parenting a child with diabetes
		Conflict in parental role
Support	Support	Parental support
		Peer support
	Role of others (Parent)	Peer support
		Wider awareness
Long term management	Integration	Acceptance
		Responsibility
	Balance	Good enough
		Sharing responsibility

3.5.1 Emotions

All of the adolescents reported experiencing painful and difficult emotions associated with their diabetes. They shared feelings of isolation and fear, as well as those of guilt and anger.

For the adolescents, feelings of isolation had been particularly strong around the time of diagnoses. They were particularly intense when there were tensions in relationships which provided a source of support.

“Like having a fall out with your friends and your family, you just feel alone, and you just want to curl up and die”

Adolescents also expressed how they felt overwhelmed and exhausted by their diabetes, with fears about future health complications.

“there’s something wrong, it’s eating away at my body”

Adolescents shared their feelings of guilt about the inconvenience they perceived others in their lives experienced as a consequence of their diabetes. There was a sense of self blame, and an inappropriate degree of responsibility for the actions of others.

“When I was in hospital, when I was diagnosed (...) I wasn’t really happy that my Mum was always coming out to check (...) she had to stop work for about a week, just to come, because she really wanted to come and see me, but I said to her it was alright (...) but she liked to come and see me and that, and I felt bad, that she kept on coming”

For the adolescents, many of their emotions had been most salient around the time of diagnosis. This is consistent with the literature as many children have adjustment problems soon after the diagnosis of diabetes (Kovacs, Feinberg, et al., 1985). As time elapsed and the adolescents adapted to their chronic illness it was the emotions of anger, and predominantly a sense of injustice which remained. These are not unusual for people with diabetes (Rubin & Peyrot, 2001). For these young people, living with diabetes is a source of frustration and irritation, particularly when they can not understand their illness, struggle to control it, or feel their efforts go unnoticed. In a discussion about sugary treats, one participant expressed her frustration at needing to be strict with her diet whilst others could afford to be more relaxed.

“If I get something like that it just peaks up straight away, I don’t know why that is (...) (It’s) unfair, if I could do that”

The pattern of the young people’s specific emotional experience was not explicitly explored in this study, but research suggests that after initial adjustment, children

with diabetes have an equivalent status to children without diabetes. However, by 2 years post diagnosis, adolescents with diabetes are known to have experienced twice the amount of depression and adjustment problems as their peers (Grey et al., 1995). Depression is significant in diabetes since the helplessness and hopelessness often associated with the condition may contribute to a vicious cycle of poor self-management, worse metabolic control, and the exacerbation of depression (Rubin & Peyrot, 1994).

Parents reported similar emotions to the adolescents, commenting on their experience of managing diabetes from a carer's perspective. Just as for the young people, the period of diagnosis had been very difficult. The parents shared feelings of anger and guilt, as well as feelings of anxiety for both the present and the future, and a sense of burden. They shared a highly critical attitude of themselves and expressed self doubt and guilt. These feelings of self doubt and inadequacy generated a desire for reassurance

“at the end of the day, you as a parent is an extra burden, I mean every parent wants their child to be perfect health wise and you know, she's our baby, and you can't always help (...) we could do with somebody to give us that added confidence and sometimes to say “You are on the right track””.

“I felt very guilty about it (...) I can not be there at every meal time (...) arranging everything for her (...) we have to trust each other (...) I just felt I was the big bad wolf all the time and that wasn’t good”

For all of the parents, their child’s illness generated feelings of anger, with particular reference to the reactions it received from others. The mothers shared their frustration at the inadequate recognition, empathy, and support provided; and in particular the role of the school and the wider community. One mother identified a culture of blame due to poor awareness of type 1 diabetes.

“she gets this from children at certain times that do think that it’s your fault that you’ve not been eating the right food (...) you know children do feel stigmatized, in the sense that you know, it’s not being put through properly on the TV and media”

Parents spoke of their worries about their child’s control of their diabetes and the impact it may have on their lives in the future. Almost all reported they ‘just wanted their children to be okay’.

“you want them to be healthy, you don’t want them to have any problems like bad feet and go blind and all this lot (...) I want them to be, I want them to have kids and be happy, because that’s all that matters that they’re happy and they’re well (...) I just want them to be okay”

For both children with diabetes and their parents, their negative feelings can in part be attributed to an inefficacy for unfulfilled aspirations (Bandura, 1997) and dissatisfaction with their current behaviours or performance. Early research has estimated that one third of mothers of newly diagnosed children exhibit significant depressive symptoms (Kovacs, Finkelstein, et al., 1985) and that mother's of children with chronic conditions experience significant care giving burdens which interferes with their ability to access appropriate support (Stewart et al., 1994). In contrast to the adolescent's experience, the strength of the mothers' emotions remained relatively stable over time. Parental worry about children with chronic illnesses has been noted in other studies (Cappelli et al., 1989) and may relate to the intrusive nature of diabetes management, which has previously been associated with significant stress in parents of young children with diabetes (Hatton et al., 1995)

3.5.2 Identifying with illness

The adolescent could be seen as split between her normal teenage self and the self with a chronic illness. This domain relates to the adolescent and their parents need to firstly understand the changes and development of the teenage years, and their need to gain an understanding and conceptual framework for the role of a chronic and potentially life changing illness within this. Both the adolescents and the parents reported difficulty in integrating these concepts although the splitting was more marked within the parental discourse.

For the adolescent, this domain incorporates themes of being a teenager, having diabetes, and the conflict in identity. For the parents, this domain recognises the struggle for the parents in offering adequate parenting, and the specific difficulties in providing care for an adolescent who can sometimes be seen as two separate parts: the teenager and the child with a chronic illness. The parent's discussion revealed distinct themes of parenting a teenager, caring for their child with diabetes, and the inevitable conflict which occurs between these roles.

The adolescent faces considerable difficulties as they begin to develop their identity. The positions of being a teenager and of being a young person with diabetes created conflict in the form of competing priorities and a sense of being identified by their illness rather than individual or personality traits. All of the adolescents made comparisons to their friends and peers, they didn't want to appear different because of their diabetes nor did they want the commitments of their diabetic regime to interfere with their pursuit of normal adolescent activities.

“you feel tired more, you feel more tired in the morning as well because it's taken more out of you (...) so you can't stay up as late as they would and you feel really knackered in the morning and you really suffer”

Identifying with themselves as normal teenagers was a challenge for the young people. They reported feeling controlled by their diabetes and the demands of their self management regimen, due to the powerful consequences of poor adherence.

They also made many social comparisons, wanting to be the same as their friends with a desire to be healthy and well in the future. For some, this motivated them to follow their prescribed regime.

“just like (...) said, I don’t want to be ill when I’m older, I want to be healthy, and I won’t want it to get in the way of what I do”

The parents also spoke of their child’s needs to be socially included. They discussed the developmental process for their children and reflected on the importance of achieving inclusion. All of the parents spoke about how their children engaged in the ‘typical’ teenage life style.

“anything that makes her different really, is the part that she finds difficult”

The adolescents associated having diabetes with a loss of control, restricted choices and the potential to remove enjoyment from their lives. They also acknowledged that their coping abilities varied, so that sometimes it seemed easy to manage, whilst at other times it was a real struggle.

“it just seems like a chore, you don’t really want to do it but you know you have to”

“you just want to be able to do stuff like everyone else, you don’t want to be having to laze around everywhere whilst everyone else is having fun. That takes the fun out of life”

Other research on chronic illness is consistent with these adolescents’ experiences. In Woodgate’s (1998) study, adolescents perceived their life as more difficult, experiencing extra effort, restriction, pain, and additional worries because of having a chronic illness. This made it difficult for them to attain the integration they craved during this period and meant that sometimes they prioritised their need for inclusion above the demands of their diabetes self management. As a consequence, this could create conflict within both the family and themselves.

For the parents, caring for a child with diabetes was about making sense of their child’s illness. These parents adopted a task focused approach, developing their sense of mastery or self efficacy, knowledge, and empathy. All of the parents spoke about the process of gathering information, learning about their child’s diabetes and supporting adherence to their prescribed regimen.

“you learn, you know you learn a lot, and I suppose it’s the best way really (...) you just don’t do it overnight, it takes time”

The mothers also spoke about their attempts to understand what their children were going through, and to provide adequate support.

“they can be carefree but now they have to think more (...) she did initially accept it but I think she’s kind of gone into more things about what might happen (...)I just keep a good eye on it, I just hope (...) .if we can just keep her healthy until she does finally click into herself”

For the parent who also had type 1 diabetes, the process was much easier. This is consistent with past interventions which have used parental simulation of diabetes management to help them gain a more empathic understanding of the complexities of diabetes (Satin et al., 1989).

For the adolescent, their source of internal conflict was about having diabetes, and how the requirements of managing their illness competed with other priorities in their lives. They faced many temptations which sometimes seemed more important than their diabetes. The adolescent’s reports of feeling stigmatised and depersonalised by their diabetes were powerful and highlighted the young person’s difficulty in attaining a sense of self-concept in addition to their illness.

“I don’t want to be treated different (...) I just want to be like a person, you know, be treated the same (...) I just want people to you know, to like me, for who I am”

This pervasive fear of stigma and of being different is consistent with the expressions of adolescents with diabetes in other qualitative research (Schur et al., 1999). It has been suggested that in order to contain the sense of being different, young people seek to develop an identity that is relatively independent of their diabetes. This is clearly important for young people since not separating the adolescent and his/her illness has previously been reported as an ‘annoying’ consequence of parent worry and intrusive behaviours (Weinger et al., 2001),

These experiences are uniform with the theory of ‘biographical disruption’ (Bury, 1982), whereby the young persons previously held view of both themselves and their future is challenged following diagnosis of a chronic illness. Schur et al (1999) propose that adolescent’s who have a chronic illness and accompanying feelings of loss of self may find it harder to develop their sense of self in comparison with adolescents who are not living with chronic illness. This was not something which the parents commented on but one parent did refer to her daughter’s propensity to completely reject her illness in a conflict situation.

“I thought I’m not getting into this constant battle with her (...) I can’t afford to ostracise her, or make things so unpleasant that we don’t want to live together (...) it makes it so unpleasant you don’t want to turn them against it so they think “Oomph”, and they want to try to pretend they haven’t got it anymore, or think all you want to do is nag nag”

This rejection is most likely a form of adaptive denial, as documented in earlier work by Seiffge-Krenke (1990), used to protect the individual, by distancing themselves from the pain and loss associated with the reality of their illness.

Supporting the contradictory positions of helping their child feel normal, versus protecting them as Mothers, and recognising the special needs of their illness, was a real challenge for the parents.

“we don’t want them to feel different at school, but they are, they do have special needs where they have got to be (...) they are different from the others (...) like it or not (...) and they’ve got to be careful on certain things”

This mirrors the findings of Schur et al, (1999), in that just as the young person goes through the process of learning to live with their diabetes and establish an optimal relationship, the parents must also go through a similar process and learn that their child with diabetes does not need to occupy a sick role.

3.5.3 Support

For the adolescents, this domain covered two themes, support from parents and support from peers.

A highly significant finding is the recognition that whilst parents and peers could provide similar types of support to the adolescent, their reception was very different. On the whole, the adolescents were rejecting of their parents support, they spoke of conflict and a sense of being misunderstood. Adolescents described how they preferred to manage their illness on their own rather than accepting their Mothers help. They appreciated the concern of their parents but said they could manage alone. Three of the adolescents did not like their parents checking up on them or nagging. They said this checking was annoying and perceived it as blocking their growing sense of autonomy. Conflict between the adolescent and their parents regarding their diabetic regimen was attributed to a poor level of understanding.

“if they ask you all the time it does get annoying (...) I don’t really like it when people ask me all the time (...) she keeps saying the same things, but I know what I’ve got to do, but she thinks that I won’t do it or something and that’s why she keeps asking me (...) I’ve done it without her help, I can do it myself”

In contrast to the support provided by their parents, they welcomed their friends checking and reminders, viewing them as encouraging, supportive and comforting, and sometimes even requesting the kind of policing they rejected from their parents. The adolescents expressed a sense of security in their peers to support them, ranging from helping them avoid temptation, to being available with sugar and supplies if

they go low, recognising the painful aspects of their regimen, like the injections, and providing reminders.

One described how she enlisted the support of her friends to avoid temptation.

“There was this time when I was actually buying quite a few sweets and that, I was just going through a phase of getting sweets and having them in the shop (...) and then like I thought “Oh that’s enough now”, so I had to tell my friends “like if you see me buying sweets in the shop, or eating anything sugary, tell me off and don’t let me get it””

It is unclear why this pattern of discrepancy, in the receiving of social support occurs, but literature from research into adults with diabetes and their spouses propose an interesting process of how the individual with diabetes evaluates and responds to spousal help. The goal is to balance the disease demands, and their spousal concerns, with their own needs for self esteem and autonomy (Bailey & Kahn, 1993). The key factors are the individual’s perceived need and the perceived motivation of the helper. Applied to this study, with adolescents and their parents, the responses of the young people follow a similar pattern. Help from parents is rejected, as it conflicts with the adolescent’s pursuit of autonomy and independence, and results in a sense of being misunderstood. The only exception is the young person whose Mother also has diabetes, for whom empathy and understanding were not an issue, and a clear shared bond was established.

“it’s been easier for me, because my Mum’s actually a diabetic herself, she’s type 1, so she like understandings everything....my Dad and my Brother, they can only do so much”

Support from their peer group is very important for young people with diabetes and research findings have proved it can improve short-term metabolic control (Anderson et al., 1989), Further, consistent with Charmaz’s (1983) proposal, receiving any positive reflection from their peers may help the young person with diabetes develop their sense of self within the context of their chronic illness, or increase their sense of being accepted (Baumeister & Leary, 1995).

For the parents, this domain was primarily about the role of others in their child’s lives. The parents did not make any specific references to the support which they offered to their children, this was because their input and support was an underlying theme of the whole focus group. The support they referenced as valuable, consisted of that provided by the child’s family, friends, and peers, and that offered by the wider community.

The parent’s welcomed the input of friends in supporting their children, as well as that provided by other significant individuals, but shared doubts about the adequacy of this support, in particular the knowledge of the supporters and their view of diabetes.

“friends and family will help at first, or remember you’re a diabetic when they’re eating certain things around you (...) but after a while, they forget (...) you’ve got to remember this is long term, it doesn’t go away after a week (...) it’s there (....) they’ve (child with diabetes) always got to remember because if they don’t they’re going to get punished for it”

These doubts may represent a form of self protection for the parents, externalising their anxiety about their own support being rejected (and as a part of this, their role as protectors), their child’s health needs not being met, and the potentially life threatening consequences which could occur.

The parents suggested that a broader awareness of type 1 diabetes within the wider community would be beneficial and further help others provide adequate support. They spoke of the importance of people understanding their children’s experiences and how this may impact on their children’s treatment. The mothers stressed the importance of education, and in particular the need for others to achieve a sufficiently balanced view of their child’s illness.

“I don’t know how you get round people’s individual perceptions and how you balance it, because it can’t be too light that people don’t take it seriously, but if you go the other way then people worry, because I know that since ‘C’ has been diagnosed....certain teachers are very quick to say “You must come and take her home””

3.5.4 Long term management

This final domain comprises the adolescent expressions of integration, pertaining to acceptance and the assumption of responsibility, and the parent's expressions of balance, being a good enough parent, and sharing responsibility with the adolescent.

For the adolescent, this last domain represents a progressive step towards integrating the demands of self management with the competing priorities of adolescence and is consistent with Newman and Newman's (1991) modification of Erikson's model of psychosocial development. The dilemma and main process for the young person during this time is achieving group identity. The young person attempts to affiliate themselves within a group to experience a sense of belonging whilst maintaining his/her own personal goals and individuality. In this study, the young people with diabetes seemed to describe two distinct life tasks, the management of their diabetes and maintaining good health on the one hand, and obtaining social acceptance and fitting in with the group on the other hand. They discussed a range of coping strategies. One participant spoke about using positive thinking, and demonstrated a mature appraisal of her coping abilities since receiving her diagnosis.

“When you first find out you feel like really shocked, and you get like loads of mixed feelings, so you think like “Why me” (...) but then you just adapt, well you just make it adapt to you really (...) and you've got to think positively, because if you think negatively it won't get you anywhere”

Adolescents accepted the responsibility for decisions about their diabetes and they expressed a sense of confidence at having control in this way.

“I’m quite independent really (...) I think of it for myself (...) I do it for myself”

One participant went beyond this by recognising that the process of self management was difficult but necessary, and for her, a part of the acceptance process was a resignation to the demands of having diabetes.

“I mean you’re mainly going to get ill if you don’t like look after yourself so you just tend to do it”

Along with the transitions made by the young people, representing the course of their diabetes and the development of long term management approaches, this period is also marked by changes for the parents. The parents begin to accept their limitations, and integrate an ideal of being a ‘good enough’ parent whilst sharing the responsibilities of their child’s diabetes management with an increasingly mature adolescent. All the respondents recognised that they could best support their children by encouraging and facilitating their children’s own choices and decisions about their diabetes care. The notion of shared responsibility, expressed by all the parents, indicates the balance and trust achieved in order to facilitate successful management.

“I make sure I’ve got everything there, I give her the time (...) .and just trying to find things, that you can just keep slotting in, very discreetly (...) that’s she’ll eat”

“she tends to do it all for herself, but I just ask because (...) it’s just the way she works”

“I have to rely on her to be able to look after herself when I’m not around”

The parents acknowledged that they retained a need to check their child’s progress, but they tried to do this as unobtrusively as possible, recognising their child’s inherent need for a sense of autonomy. Managing parental emotional distress through processes of overseeing and distancing has previously been documented (Dashiff, 1993).

Just as the adolescent seeks to find a balance between two competing life tasks, the parents struggle with a similar pattern of conflict. This is between caring for their child with a chronic illness, and supporting their pursuit of independence and personal growth. By avoiding over-restriction of opportunities for making and maintaining peer relationships, the parents are instrumental in supporting their adolescent through this developmental stage of group identity (Newman & Newman, 1991) which is consistent with past research highlighting the importance for parents

of adolescents with diabetes to support normative development (La Greca et al., 1995).

The adolescent can be seen to integrate their own individual identity, accepting and taking responsibility for aspects of their diabetes care, and balancing this with their pursuit of other life goals. The pursuit of these goals requires effortful motivation. Based on research into the life tasks of students using theories of effortful motivation, goal pursuit requires self reflection, commitment, and effort (Cantor & Fleeson, 1994). Progress comes at some cost and requires the negotiation of obstacles, coordination of competing goals and management of self doubt and anxiety (Cantor & Blanton, 1996; Bandura, 1986). As has been demonstrated in this study, the demands of competing life tasks, and managing multiple demands can lead to role strain and burden. In order to prioritize these conflicting pursuits the adolescents or parents may choose to alternative their emphasis, or seek to consolidate the pursuit of multiple tasks (Cantor & Blanton, 1996). The adolescent's spoke about sacrificing perfect adherence to their diabetic regime for the sake of making progress on the integration and socialization life tasks, an example of alternating emphasis; and the parents spoke about consolidating, supporting their child at a distance, facilitating their child's personal decisions about self care and managing their protective fears and anxiety.

Schur et al (1999) have discussed this period as the young person's learning to live with diabetes, seeking an optimal relationship with their diabetes, whilst gaining a

balance with the rest of their lifestyle. The young people in this study described cognitive coping strategies, consistent with the downward comparisons reported in Schur's study (1999) and previously by Buunk & Hoorens (1992). Social comparisons were made with others perceived to be in worse situations. Also, as has been documented in previous studies, a personal feeling of self-worth and self-efficacy were fundamental to how the young people were able to cope with their self care (Woodman, 1999).

3.6 Limitations and suggestions for further research

IPA is looking at the experiences of the adolescents and parents that participated in this study, and the researchers' interpretations of them. It is not intended to be generalised and the results cannot be considered to be representative of the wider population (Eiser & Twamley, 1999). All of the participants in this study were female and aged 14. It is probable that their male counterparts, as well as older adolescents in general, could face other issues as the adolescent experience tends to be rather different across gender and age. Similarly, all of the parents that participated were mothers, and the research evidence suggests that the responses from fathers may be very different (Dashiff, 2003). More generally, research indicates that participants and non participants may show group differences relating to self care adherence. There is also a limitation of focus group methodology in that the group consensus may inhibit conflicting or differential comments.

This study utilised a small convenience sample. More than one focus group had been planned but there was a low response rate, and attendance for the scheduled group was poor. However, whilst disappointing, the small sample size within this study is not uncommon within medical focus groups (Greenbaum, 1998), and did allow more opportunities to elicit more information from each of the individuals.

It was striking that on the whole, the discussion in the young person's focus group was significantly more positive than that of the parental group. In listening to the parent's talk about their children it became apparent that the young people may have portrayed themselves as better than they actually are, in terms of self management and adherence. There are a number of explanations for this, it may be reflective of a generalised coping strategy, a product of the group dynamics with none of the young people wanting to admit to specific difficulties, or a consequence of context, given that the group took place at the hospital which the young people would attend for their outpatient appointments. The optimism of youth, and a sense of hopefulness and positivism at facing the future are also likely components. In this way, whilst the parents may only be able to see the limitations of their child's illness, linked to their own emotional distress at having an 'ill' child and the threats this presents to the parental protector role, the adolescent's attention is primarily on other aspects of their life, the excitement of the path to adulthood, and beyond.

It is not possible to ignore the role of the researcher in both the focus group dynamic and the analysis process, indeed this is an important part of qualitative research

enabling the reader to better interpret the researchers' data and understanding (Elliott et al., 1999). It is likely that the researcher's introduction, as a trainee clinical psychologist, and the presence of an observer, introduced as an experienced researcher in diabetes, affected the nature and extent of the participants' accounts, although the discussions remained frank, wide-ranging and emotive. Perhaps the suggestion of a psychological focus led the participants to offer more emotional accounts than otherwise. It is also likely that the accounts were enhanced, particularly for the parents, as this was the first time their views had been invited outside of the normal clinic setting, where their own needs run secondary to those of their children. It is likely that their disclosures were facilitated by the interviewer's clinical training and past experience in helping people to talk about sensitive topics.

Future studies could explore many of these issues in more depth using semi-structured interviews with young people at varying stages of adolescence, and diagnosis, and their parents. It would then be appropriate to focus on those facets of the adolescent's experience categorised as most difficult and address how these can be managed both clinically and socially.

3.7 Conclusions and implications for practice

The concept of diabetes self management has recently been clarified as "an active, daily and flexible process in which youth and their parents share responsibility and decision making for achieving disease control, health, and well-being through a wide

range of illness related activities” (Schilling et al., 2001). This study provides a useful insight into the cognitive and affective processes underlying the complexity of diabetes management in adolescence. It highlights the perceptions of both the young people and their parents, and how each, in a different way, finds it difficult. There is the struggle for normalisation, peer acceptance, and the sharing of diabetes related responsibility. The central feature of diabetes management as described by the young people in this study, is the achievement of a balance between self care adherence and having a life worth living. In recognising this, health professionals need to place the patient and their co-managers at the centre of goal-setting in diabetes care, as stipulated in the empowerment paradigms (Anderson et al., 1995). Diabetes management is recognised as a shared process between parent and child. It is important that the perspectives of both parent and child are aired in order to understand how these may be impacting on their behaviours, as well as to encourage effective communication.

For both the young people and their parents, long term diabetes management and adolescent development was about juggling conflicting priorities. They carry out their health management tasks in the context of their ongoing lives (Radley, 1994) and in this way, the concepts of instrumentality and self efficacy are central.

Psychologically, these judgements of personal capability can be used to positive consequence when the individual is pursuing a task in which he / she experiences difficulties (Cantor & Blanton, 1996; Bandura, 1986). Therefore whilst diabetes self management provides a huge challenge for the young person, or indeed their parents,

the achievement of successful management, a strong sense of efficacy, and faith in oneself can be utilised as “a bulwark against all of life’s challenges, not only those presented by diabetes” (Rubin & Peyrot, 2001). The young people in this study were able to identify some positive aspects of their diabetes, namely being more responsible, maturing earlier and in some cases, receiving special treatment. It is suggested that identifying and discussing any positive diabetes-related experiences can help young people and their parents put the emotional consequences of diabetes in perspective (Rubin & Peyrot, 2001). Previous research has shown that these experiences can enhance motivation and relieve distress.

Therapeutically, these findings indicate that parents of young people with diabetes may not receive adequate support. Our findings indicate that a support group, providing a space for education, shared experience, and the discussion of fears and anxieties would be of significant benefit to these parents. There would also be value in providing the opportunity for emotional expression in contacts between health professionals and family members (Dashiff, 1993).

Throughout the research process I have been struck by the apparent resilience and robustness of these young people, of their resourcefulness in managing their illness and of the optimism with which they approach the regimen demands. In many ways, from hearing the young people speak in the group, it would be easy to overlook the seriousness of their condition, whilst for the parents, the weight and the burden of this chronic illness was clearly recognisable. Both focus groups spent time sharing

their experiences, trading stories and management tips, but the young people seemed less at ease throughout the process which I believe reflects the context, and their understandable reticence to devote so much of their social time to discussing their diabetes. In contrast, the parents welcomed the opportunity; they felt they benefited from the sharing with other parents which may have gone some way to lifting the sense of burden and guilt.

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CHAPTER 4: REFLECTIVE REVIEW

Reflective review

Word Count: 2031

Chapter Four: Reflective Review

“Our greatest glory is not in never falling, but in rising every time we fall”.

Confucius

4.1 Introduction

This paper focuses on issues arising from the research process. It highlights areas of particular difficulty and those that have warranted reflection and exploration. Within this context, I will consider recruitment, ethical considerations, methodological issues and personal reflections and learning. This paper includes comment on the Quantitative-Qualitative debate, reflections on the impact of the research on the participant, and offers a personal context to the studies' pivotal themes of identity and self efficacy.

4.2 Recruitment

Despite conducting two very different types of research, in different areas, and different clinics, the same issues and difficulties in recruitment emerged. I had assumed that there would be some sort of relationship between my level of effort, the efforts of the committed Diabetic Specialist Nurses who rallied the enthusiasm of the potential participants, and the final numbers of recruitment, but this was not always the case. For the quantitative investigation utilising a survey methodology

the recruitment rate was less than 50%, but of those who consented, the return rate was very good (probably due to my continued presence at the clinic, peering over my glasses and checking their progress like a school teacher). This was in contrast to the qualitative study which despite a similar recruitment rate, produced disappointing numbers when attempts were made to confirm participation. Countless telephone calls ensued, attempting to organise suitably timed focus group meetings, along with letters of confirmation and reminder telephone calls, and yet the final group of participants represented only half of the adolescent-parent pairings who only the previous evening had confirmed their attendance. It is my belief that these difficulties speak volumes about not only the experience of chronic illness in childhood and adolescence, coping strategies, and the continued challenge of management and acceptance, but also the popular perceptions of research, and the bad feeling and anxiety created by some terrible revelations in the press of unethical medical investigation at large hospitals. This unwillingness has previously been reported with other medical focus groups (Greenbaum, 1998) and may account for the relatively small number of studies which have previously employed this methodology.

4.3 Ethical considerations

In their ethical principles for conducting research with human participants, the British Psychological Society (BPS, 2000) highlight the difficulties in obtaining consent from the young, and stress the need to “recognise and uphold the rights of

those whose capacity to give valid consent to interventions may be diminished”. For inclusion in the study, consent was required from both parent and child, in all age groups, and whilst joint agreement was obtained from all of the participants included in this study it would be naïve to suggest the motivation or enthusiasm was the same for both parties. This was a difficult path to navigate. In some cases, I had a consenting parent extolling the virtues of research and their joint enthusiasm for participation (presumably a reflection of that parent’s hopes and fantasies that in the future things may improve), whilst on the other I had a ‘consenting’ child, huffing as they turned the pages of the questionnaire booklet, desperate to finish, for whom inclusion in the study may well have been notched as ‘yet another’ negative sequelae of having diabetes. In every event when this occurred, I was probably overzealous in reminding the participant of their right to withdraw consent at any time, yet all of them refused. So I’m still unsure what this is all about. Perhaps it’s classic teenage disinterest, huffing as a product of the ‘Kevin syndrome’, a measure of distress at being faced with an avoided reality, or something else entirely. I wish I knew, and in the light of the research findings from paper 1, which represent very different results from two stages of adolescence, I would like to investigate this further.

4.4 Methodological Issues

4.4.1 Quantitative vs. Qualitative

Throughout this research process I have become even more aware of the stark differences between the two methods of enquiry employed in this study, and am pleased to have used such contrasting strategies, neither of which can be differentiated as the easier option.

Paper 1 used a survey methodology for a cross sectional study and in doing so provides a 'snap shot' approach. Using predetermined categories of analysis on instruments pre-selected for their validity and appropriateness, the data was statistically aggregated, providing a broad, generalizable set of findings which is presented succinctly.

In contrast, Paper 2, using focus groups, provides a wealth of detailed information about a much smaller number of people, undoubtedly increasing the understanding of those cases under study, but reducing the scope for generalisation (Patton, 1990). Whilst the concept of the researcher as the instrument of enquiry can be seen as a huge threat to the validity of the second study, I am in full agreement that "this loss in rigor is more than offset by the flexibility, insight, and ability to build on tacit knowledge that is the peculiar province of the human instrument" (Guba & Lincoln, 1981). The chosen analysis for the qualitative paper is somewhat controversial

since there is some scepticism about the appropriateness of conducting IPA, “an approach committed to the detailed exploration of personal experience” (Smith, 2004), with focus groups, which have traditionally been used to establish themes or discourses present in a group. In response to these sceptics, I felt confident that the transcripts from these focus groups presented idiographic accounts, and support Wilkinson’s (2003) suggestion that in certain circumstances, focus groups facilitate personal disclosure.

As well as the conceptual differences between these two traditions and the consequent differences in overall practice and methodology, I have also become aware of the differing impact the approaches can have on the participants. These are addressed in the next section.

4.4.2 Impact on participant

I’ve found it helpful to consider the impact of the research process on the participant for three reasons. Firstly, it provides some tentative explanation for the difficulties securing participation within the qualitative study. Secondly, it raises the question of how different methodological approaches impact on the individual and finally, because I wonder whether there were any positive aspects for those who participated in my study.

I think it's easier to retain distance, and the effective use of coping strategies such as adaptive denial (Seiffge-Krenke, 1990) whilst participating in a quantitative study. Two crucial parts of the process involved in questionnaire completion are forced choice and anonymity. Respondents can express their feelings in a non-threatening manner without the fear of any negative consequence and can also intellectualise their experience, replacing the ownership of their personal expression with the need to adhere to set responses. When I consider my own experience of questionnaire completion for research purposes, whilst occasionally experiencing frustration and even rejection when the responses presented in no way reflected my own, I also recall a sense of relief and safety at being spared the potential pain or difficulty of expressing my own, true, feelings. I don't know if this experience was in any way shared with the participants of this study but I do know that participation and questionnaire completion evoked some strong responses from some people, particularly the parents. In a number of circumstances, following questionnaire completion, participants were anxious to discuss and share their experiences, above and beyond any requirement stipulated by the research proposal.

It is my belief that participation in qualitative investigation is more intense for the individual and as such, far more threatening. It would be interesting to investigate the differences between those people who agreed to participate in such research and those that did not. I suspect the findings would reflect a vested interest for participants in qualitative research in having a mechanism for their voice to be heard, thus negating any concerns of exposure.

It was fascinating to observe the dynamics of questionnaire completion within the outpatient department. For many of the adolescent-parent pairings who opted to complete their questionnaires at clinic, what was most striking, was the camaraderie and sharing the exercise engendered between parent and child. The exercise seemed to generate a forum for discussion between them, I observed them swapping completed forms to see each others 'answers', checking out responses to certain questions, and saying things like "I had no idea you felt like that". All of the research suggests that the facilitation of continued communication with regard to the tasks of diabetes management within the family is essential (Anderson et al., 1990; Burroughs et al., 1997) and whilst artificially created, participation in this research presented an opportunity for parent and child to question a range of diabetes related activities.

4.5 Personal reflections and learning

4.5.1 Issues of identity and the Practitioner-Researcher

One of the key themes to emerge from the qualitative paper examining adolescents' and parents' experience of diabetes was their difficulties establishing a sense of identity in the face of conflict between the 'normal' self and the 'ill' self. It is therefore slightly ironic that throughout the research process I have struggled to hold on to a sense of my own professional and academic identity. The idea of a practitioner-research synergy is encouraged within the psychological community but

there is no guidance on managing such dual-role relationships. It is difficult to recognise the Practitioner element of the synergy when beginning the seventh consecutive day of number shuffling and data analysis. Likewise, when advice on therapeutic intervention is requested by a desperate and tearful parent, “grateful for the opportunity to talk”, retaining the role of Researcher feels detached and cold. However, on reflection, it is my ability to wear both of these hats at once, perhaps on different tilts, that has enabled me to draw conclusions, interpretations and suggestions for future research. I would definitely like to think that the serenity of my clinical / practitioner persona helped me through many a fraught research moment and enabled the containment of the flappable researcher within.

4.5.2 Self efficacy

Just like the identity theme has dictated my sense of self throughout the research process, the concept of self efficacy has determined my motivation, perceived capability and perseverance. Bizarrely, the Bandura bible ‘Self efficacy – The exercise of control’ (1997) has been, in itself, a source of motivation. On recognising that my self-esteem (frequently to be found in tatters across the Midlands) affected neither personal goals nor performance, I could focus my energy on reasserting my capabilities and being confident in my efficacy to mount and sustain the efforts required to succeed and complete the thesis, although of course, this isn’t as easy as it sounds. The biggest part of this struggle has been my perceived lack of expertise and lack of confidence. However, I have been fortunate

enough to be able to conduct different parts of my research as part of a team whereby I could not only benefit from various opportunities to assess reliability of data as well as share perceptions about important issues but also benefit from a sense of collective efficacy, an emergent attribute of the group dynamics. This concept, shared between supervisor and student, or within the particular research group, held all the cards in re-establishing my own individual concept of self efficacy, and for that, I will always be grateful. Also, somewhere along the line, around hand in date, the self esteem returned!

4.6 A final note

Research is exhausting and the experience of completing these papers has been a challenge at every turn. The process began with the rigours of completing the research proposal, attending ethics boards, and recruiting participants and ends, hopefully, with a name in print. Along the way the demands have been multiple, I've lost count of the number of times that somehow I've 'forgotten' the research question and suffered the indignity of paralysing anxiety, but somehow it has to have been worth it. My communication skills have improved immensely, through explaining my project rationale to a hostile ethics board, listening and reacting, defending my ideas and opinions, and redirecting and redefining my objectives (Hakel et al. 1982). Metaphorically, I've also acquired the skills of an experienced optician in repairing the trampled remains of my rose tinted spectacles, which I'm

pleased to say, remain in pride of place at the end of my nose, ready for the next research exercise.

4.7 References

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Appendices

COVENTRY UNIVERSITY - SCHOOL OF HEALTH AND SOCIAL SCIENCES

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: **HEIDI GIBBINS** 2. Course: **CLINICAL PSYCHOLOGY**
(BLOCK CAPITALS)
3. Title of project: **INVESTIGATING MOTIVATION FOR DIETARY SELF-CARE IN ADOLESCENTS WITH TYPE 1 DIABETES.**
4. Summary of the project in jargon-free language and in not more than 120 words:

Sample:

150 ADOLESCENTS (12-18 yrs) WITH TYPE 1 DIABETES
 Research site: **AND THEIR PARENTS/CAREERS**
ROOTH & BLOSSGROVE APT, BIRMINGHAM CHILDRENS HOSP.
 Design (eg experimental): **CROSS-SECTIONAL: CORRELATIONAL, WITHIN-SUBJECT DESIGN**
 Methods of data collection: **ALL PATIENTS WITH TYPE 1 DIABETES AGED 12-18 yrs AND THEIR FAMILIES ATTENDING PARTICIPATING DIABETES CLINICS WILL BE INVITED TO TAKE PART IN THE STUDY BY LETTER SENT BY THEIR CLINICIAN.**
IF CONSENT TO PARTICIPATE IS GIVEN BY ALL PARTIES, THE ADOLESCENT & THEIR PARENT WILL BE INVITED TO FILL OUT SOME QUESTIONNAIRES EITHER AT THEIR OUT-PATIENT CLINIC APPOINTMENT OR AT HOME.

Access arrangements (if applicable):

ACCESS FACILITATED BY DIABETES NURSE SPECIALISTS.

5. Will the project involve patients(clients) and/or patient(client) data?

Yes ☒ No ☐

6. Will any invasive procedures be employed in the research?

Yes ☐ No ☒

7. Is there a risk of physical discomfort to those taking part?

Yes ☐ No ☒

8. Is there a risk of psychological distress to those taking part?

Yes ☐ No ☒

9. Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available?

Yes ☐ No ☒

10. Is it intended to seek informed consent from each participant (or from his or her parent or guardian)?

Yes ☒ No ☐

Student's signature:

Supervisor's signature:

Date:

24/5/03

Access arrangements (if applicable):
FOR COMMITTEE USE:

Immediate approval ☒Referral to local Hospital Ethics Committee ☐Referral to full School Committee ☐

Decision pending receipt of further information
 (specify below) ☐

Committee Member's signature:

Date:

24/5/03



Thames Valley Multi-centre Research Ethics Committee

Dr Arie Nouwen
Senior Lecturer in Clinical Psychology
University of Birmingham
School of Psychology
Edgbaston
Birmingham B15 2TT

Chairman: Dr CJ Barton
Vice-Chairman: Mr P Tausig
Administrator: Ms Iwona Nowicka
Assistant Administrator: Ms Lavenda Lee

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11 June 2003

Dear Dr Nouwen

MREC Ref No: 03/12/026
Title: Motivation for dietary self-care in adolescents with type 1 diabetes: a comparison of Self-Efficacy Theory and Self Regulation Theory

The Chairman of the Thames Valley Multi-centre Research Ethics Committee has considered the amendments submitted in response to the Committee's earlier review of your application on 15 April 2003, as set out in our letter dated 22 April 2003.

The documents that have now been approved are as follows:

1. *Patient Information Sheet & Consent Form (Parent Version), version 3 dated May 2003*
2. *Patient Information Sheet & Consent Form (Young Person aged 12-16 Version), version 3 dated May 2003*
3. *Patient Information Sheet & Consent Form (Young Person aged 17-18 years), version 3 dated May 2003*
4. *Study Protocol, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
5. *Sample letter of invitation/introduction, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
6. *General Information – Adolescent, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
7. *General Information – Parent, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
8. *"Following my dietary plan for diabetes", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
9. *"Beliefs about Diabetes", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
10. *"Social Self Efficacy – Adapted", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
11. *"Diabetes Social Support Questionnaire – Family version – Adapted", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*

12. *"Diabetes Social Support Questionnaire – Friends version – Adapted", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
13. *"Diabetes Self-Care Activities Questionnaire – Adapted", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
14. *CDI-S Questionnaire, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
15. *Life Satisfaction Scale, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
16. *"Identifying your Problem Areas in Diabetes – Teen Version, (PAID-T) (Short Form – Modified), version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
17. *"Identifying your Child's Problem Areas in Diabetes (CPAID) – Adapted, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
18. *"Diabetes Family Responsibility", version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
19. *Questionnaire Booklet Summary – Parent, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
20. *Questionnaire Booklet Summary – Young Person, version 1 dated 28 March 2003 (please note: the version number and the date have been inserted by the TV MREC secretariat)*
21. *Indemnity Insurance on behalf of Heidi Gibbins, signed by Dr Delia Cushway, Programme Director, School of Health and Social Sciences, University of Coventry, and dated March 2003*
22. *University of Birmingham Form of Indemnity, dated 12 May 2003*

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set out below. A full record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

Conditions of Approval

- No research subject is to be admitted into the trial until agreement has been obtained from the appropriate local research ethics committees.
- You must follow the protocol agreed and any changes to the protocol will require prior MREC approval.
- If projects are approved before funding is received, the MREC must see, and approve, any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.
- You must promptly inform the MREC and appropriate LRECs of:
 - (i) deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects;
 - (ii) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
 - (iii) all adverse drug reactions that are both serious and unexpected;

(iv) new information that may affect adversely the safety of the subjects or the conduct of the trial.

- ***You must complete and return the standard progress report form to the MREC one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the MREC when your research is completed.***

While the MREC has given approval for the study on ethical grounds, it is still necessary for you to obtain management approval from the relevant Clinical Directors and/or Chief Executive of the Trusts (or Health Boards/HAs) in which the work will be done.

Local Submissions

It is your responsibility to ensure that any local researcher seeks the approval of the relevant LREC before starting their research. To do this you should submit the appropriate number of copies of the following to the relevant LRECs:

- this letter
- the MREC Application Form (including copies of any questionnaires)
- the attached MREC response form
- Annex D of the Application Form
- one copy of the protocol
- the final approved version of the Patient Information Sheet and Consent Form

It is important to check with the respective LRECs the precise numbers of copies required as this will vary and failure to supply sufficient copies could lead to a delay. In addition, you should submit to LRECs only the revised paperwork reflecting the requirements of the MREC as referenced in the response form.

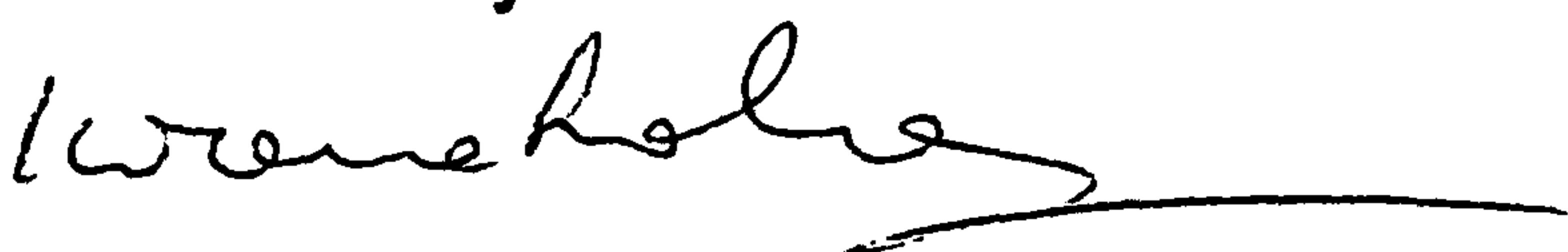
Local Sites

Whilst the MREC would like as much information as possible about local sites at the time you apply for ethical approval it is understood that this is not always possible. You are asked, however, to send details of local sites as soon as a researcher has been recruited. This is essential to enable the MREC to monitor the research it approves.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at <http://www.corec.org.uk>

Yours sincerely



Iwona Nowicka
Administrator, Thames Valley MREC

SAMPLE LETTER OF INVITATION/INTRODUCTION

Dear Patient / Carer,

Re: Research investigating self care in adolescents with type 1 diabetes.

A research study is being carried out at this clinic by Heidi Gibbins.

This study has been designed to investigate how treatment demands are managed by young people with type 1 diabetes and their families. Patients are being asked to complete questionnaires and answer questions about their experiences of diabetes, and the things that they find most helpful.

As you are currently being treated at this hospital for diabetes, the responses of you and your family would be very valuable. It is hoped that the results of this study will help other health care staff understand the needs of their patients and consequently improve services.

If you would like to take part in this study, details of which are given on the information leaflet enclosed, please complete the consent form enclosed with this letter and return it to the Diabetes team stating your preferred method of contact with the researcher (whether you would like to be contacted at your home or at your next outpatient clinic appointment). The research nurse/investigator will then contact you to arrange a convenient time to fill in a few questionnaires which should last about half an hour.

I would like to thank you for taking time to read this letter and hope to hear from you soon. If you have any queries, please feel free to contact the researchers or myself on the telephone numbers below.

Yours sincerely

Clinician's name and title:

Dept:

Telephone No:

Researchers Contact Details

Heidi Gibbins

Clinical Psychology Doctorate Course

School of Health and Social Sciences

Coventry University

Coventry

024 7688 8328

28 March 2003

PATIENT INFORMATION SHEET

(Young Person aged 12-16 Version)

1. Study title

Investigating self care in adolescents with type 1 diabetes.

2. Invitation paragraph

You are being invited to take part in a research study which is being undertaken as part of a clinical psychology doctorate training. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

The study is about finding out how you manage your diabetes, what you find difficult, and what is most helpful to you. We want to find out how you and your family are coping with having diabetes in your life, how this affects your ability to do other things which are important to you, and who takes responsibility for managing your diabetes.

4. Why have I been chosen?

All families with a young person with type 1 diabetes, aged 12-18, under the care of the diabetes team of this clinic are being invited to take part. Families at other regional hospitals (e.g. Leicester Royal Infirmary) are also invited to take part.

5. Do I have to take part?

No! It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw (leave the study) at any time and without giving a reason. This will not affect the quality of care you receive.

6. What will happen to me if I take part?

If you decide to take part one of two things will happen. You may be introduced to the person doing the research at your next clinic appointment, or he or she may contact you by telephone. You and your parent will be asked to fill out some questionnaires about your family, how you feel about your diabetes and how you manage it, who takes charge of your diabetes and how it affects your life. This will take about half an hour. These questionnaires can either be completed at the clinic (somebody will be available to help you or answer any questions) or taken home to be completed in your own time. Alternatively, it can be arranged for the person doing the study to visit you at home and go through the questionnaires with you.

You will also be asked to give your permission for access to your medical records. This is so the person doing the study can obtain information about the tests your doctor does in clinic for your diabetes.

If you agree, we may contact you in one year and ask whether you would be interested in answering the same questions again.

7. What do I have to do?

If you are happy to take part in this study, we would like you to complete a questionnaire booklet. There are no drugs or medical procedures involved in this study.

8. What are the possible disadvantages and risks of taking part?

There are no risks involved. However, if taking part in this research project distresses you, you should let us know by using the contact information at the end of this sheet. In the first instance we will discuss your difficulties with you. If you need professional help, we will speak to you about this and you may then want to contact your GP or Doctor at clinic.

Should the answers that you give indicate that you seem very sad, we will speak to you and your parents about this and you and your parents may then want to contact your GP or Doctor at clinic.

9. What are the possible benefits of taking part?

There are no direct benefits for you. However, by learning how young people and their families manage their diabetes, we hope to develop services that help us to improve the life of patients who are having difficulties in living with their diabetes.

10. What if something goes wrong?

As we said before, if taking part in this research project distresses you, you should let us know by using the contact information at the end of this sheet. In the first instance we will discuss your difficulties with you. If you need professional help, we will speak to you about this and you may then want to contact your GP or Doctor at clinic.

There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

11. Will my taking part in this study be kept confidential?

All information which is collected about you in the course of the research will be kept strictly confidential. The information about you will have your name and address removed and replaced by a code number so that you cannot be recognised from it. The information you provide will be stored in a locked cabinet at the University of Birmingham. Dr. Arie Nouwen, the study leader will ensure the security of the information you give. Only members of the research team led by Dr. Nouwen will have access to the information to calculate the results.

The answers which you provide to the questions will not be given or told to your parents nor will it be given to anyone else within the diabetes team. However, if we are concerned about your health or well-being, we may have to speak with other professionals to find you appropriate help, but we will always discuss this with you and your parents first.

12. What will happen to the results of the research study?

The results of this study may on completion be published in a scientific journal, but you will not be personally identified in any report/publication. We will inform everyone who took part through a summary of our findings.

13. Who is organising and funding the research?

The research is organised by the School of Psychology of the University of Birmingham and the Universities of Coventry and Warwick. The study is being funded by the Clinical Psychology Programme of these two Universities. Your doctor is obtaining no fee for his/her assistance.

14. Who has reviewed the study?

This research has been reviewed by the Thames Valley Multi-centre Research Ethics Committee.

15. Contact for Further Information

If you decide to take part, you will be given this information sheet to keep, together with a copy of the signed consent form.

Thank you for reading this information. If you have any matters which may concern you, or further questions, you may speak to the Senior Researcher in charge of this project, Dr Arie Nouwen, on the following number: (0121) 4147203, or to Ms. Heidi Gibbins, Trainee on the Clinical Psychology Doctorate Course at Coventry University on 024 7688 8328.

Thank you for taking part in this study.

PATIENT INFORMATION SHEET

(Young Person aged 17-18 yrs Version)

1. Study title

Investigating self care in adolescents with type 1 diabetes.

2. Invitation paragraph

You are being invited to take part in a research study which is being undertaken as part of a clinical psychology doctorate training. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

The research study is about finding out how you manage your diabetes, what you find difficult, and what is most helpful to you. We want to find out how you and your family are coping with having diabetes in your life, how this affects your ability to do other things which are important to you, and who takes responsibility for managing your diabetes.

4. Why have I been chosen?

All families with a young person with type 1 diabetes, aged 12-18, under the care of the diabetes team of this clinic are being invited to take part. Families at other regional hospitals (e.g. Leicester Royal Infirmary) are also invited to take part.

5. Do I have to take part?

No! It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the quality of care you receive.

6. What will happen to me if I take part?

If you decide to take part one of two things will happen. You may be introduced to the person doing the research at your next clinic appointment, or he or she may contact you by telephone. You and your parent will be asked to fill out some questionnaires about your family, how you feel about your diabetes and how you manage it, who takes charge of your diabetes and how it affects your life. This will take about half an hour. These questionnaires can either be completed at the clinic (somebody will be available to help you or answer any questions) or taken home to be completed in your own time. Alternatively, it can be arranged for the person doing the research to visit you at home and go through the questionnaires with you.

You will also be asked to give your permission for access to your medical records. This is so the person doing the research can obtain information about the tests your doctor does in clinic for your diabetes.

If you agree, we may contact you in one year and ask whether you would be interested in answering the same questions again.

7. What do I have to do?

If you are happy to take part in this research, we would like you to complete a questionnaire booklet. There are no drugs or medical procedures involved in this research.

8. What are the possible disadvantages and risks of taking part?

There are no risks involved. However, if taking part in this research study distresses you, you should let us know by using the contact information at the end of this sheet. In the first instance we will discuss your difficulties with you. If you need professional help, we will speak to you about this and you may then want to contact your GP or Doctor at clinic.

Should the answers that you give indicate that you seem very sad, we will discuss this with you and your parents and you may then want to contact your GP or Doctor at clinic.

9. What are the possible benefits of taking part?

There are no direct benefits for you. However, by learning how young people and their families manage their diabetes, we hope to develop services that help us to improve the life of patients who are having difficulties in living with their diabetes.

10. What if something goes wrong?

As we said before, if taking part in this research study distresses you, you should let us know by using the contact information at the end of this sheet. In the first instance we will discuss your difficulties with you. If you need professional help, we will speak to you about this and you may then want to contact your GP or Doctor at clinic.

There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

11. Will my taking part in this study be kept confidential?

All information which is collected about you in the course of the research will be kept strictly confidential. The information about you will have your name and address removed and replaced by a code number so that you cannot be recognised from it. The information you provide will be stored in a locked cabinet at the University of Birmingham. Dr. Arie Nouwen, the study leader, will ensure the security of the information you give. Only members of the research team, led by Dr. Nouwen, will have access to the information for analyses.

The answers which you provide to the questions will not be given or told to your parents nor will it be given to anyone else within the diabetes team. However, if we are concerned about your health or well-being, we may have to speak with other professionals to find you appropriate help, but we will always discuss this with you and your parents first.

12. What will happen to the results of the research study?

The results of this study may, on completion, be published in a scientific journal, but you will not be personally identified in any report/publication. We will inform everyone who took part through a summary of our findings.

13. Who is organising and funding the research?

The research is organised by the School of Psychology of the University of Birmingham and the Universities of Coventry and Warwick. The study is being funded by the Clinical Psychology Programme of these two Universities. Your doctor is obtaining no fee for his/her assistance.

14. Who has reviewed the study?

This research has been reviewed by the Thames Valley Multi-centre Research Ethics Committee.

15. Contact for Further Information

If you decide to take part, you will be given this information sheet to keep, together with a copy of the signed consent form.

Thank you for reading this information. If you have any matters which may concern you, or further questions, you may speak to the Senior Researcher in charge of this project, Dr Arie Nouwen, on the following number: (0121) 4147203, or to Ms Heidi Gibbins, Trainee on the Clinical Psychology Doctorate Course at Coventry University on 024 7688 8328.

Thank you for taking part in this study.

Centre Number:
Study Number:
Patient Identification Number for this trial:

JOINT CONSENT FORM (Young Person 12-16 years)

Title of Project: Investigating self care in adolescents with type 1 diabetes.

Name of Researchers: Dr. Arie Nouwen and Ms. Heidi Gibbins.

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2003 (version 3) for the above study and have had the opportunity to ask questions.

☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐
3. I understand that sections of my child’s medical notes may be looked at by responsible individuals from the Universities of Coventry and Birmingham or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my child’s records.

☐
4. I agree to for me and my child to take part in the above study.

☐

Please see following page.....

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM (Young Person 17-18 years)

Title of Project: Investigating self care in adolescents with type 1 diabetes.

Name of Researchers: Dr. Arie Nouwen and Ms. Heidi Gibbins

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2003 (version 3) for the above study and have had the opportunity to ask questions.

☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from the Universities of Coventry and Birmingham or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

☐
4. I agree to take part in the above study.

☐
5. I agree that I can be contacted in one year to see if I am interested in answering the questions again.

☐

Name of Young Person / Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Dr Arie Nouwen
Researcher

May 2003
Date

Signature

Please tick preferred option:

- I would like the questionnaires to be posted for me to complete at home☐
- I would like a researcher to telephone and arrange a home visit☐
- I would like to complete the questionnaires at my next out-patient visit☐
- 1 for patient; 1 for researcher; 1 to be kept with hospital notes

PATIENT INFORMATION SHEET (Parent Version)

1. Study title

Investigating self care in adolescents with type 1 diabetes.

2. Invitation paragraph

You are being invited to take part in a research study which is being undertaken as part of a clinical psychology doctorate training. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

The study is about finding out how your son/daughter manages diabetes, what he/she finds difficult, and what is most helpful. We want to find out how you and your son/daughter are coping with having diabetes in your lives, how this affects your son/daughter's ability to do other things which are important to him/her, and who takes responsibility for managing diabetes.

4. Why have I been chosen?

All families with a young person with type 1 diabetes, aged 12-18, under the care of the diabetes team of this clinic are being invited to take part. Families at other regional hospitals (e.g. Leicester Royal Infirmary) are also invited to take part.

5. Do I have to take part?

No! It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the quality of care your son/daughter receives.

6. What will happen to me if I take part?

If you decide to take part one of two things will happen. You may be introduced to the person doing the research at your son/daughter's next clinic appointment, or he or she may contact you by telephone. You and your child will be asked to fill out some questionnaires about your family, how your son/daughter feels about diabetes, who manages diabetes in the family, and its impact on your son/daughter's life. This will take about half an hour. These questionnaires can either be completed at the clinic (somebody will be available to help you or answer any questions) or taken home to be completed in your own time. Alternatively, it can be arranged for the person doing the research to visit you at home and go through the questionnaires with you.

You and your son/daughter will be asked to give permission for access to your child's medical records. This is so the person doing the study can obtain information about the tests the doctor does in clinic for your child's diabetes.

If you agree, we may contact you in one year and ask whether you would be interested in answering the same questions again.

7. What do I have to do?

If you are happy to take part in this study, we would like you to complete a questionnaire booklet. There are no drugs or medical procedures involved in this study.

8. What are the possible disadvantages and risks of taking part?

There are no risks involved. However, if taking part in this research project distresses you, you should let us know by using the contact information at the end of this sheet. In the first instance we will discuss your difficulties with you. If you need professional help, we will speak to you about this and you may then want to contact your GP.

Should the answers your son/daughter gives indicate that they seem very sad, we will speak to both them and yourself about this and you and they may want to contact the GP or Doctor at the clinic.

9. What are the possible benefits of taking part?

There are no direct benefits for you or your son/daughter. However, by learning how young people and their families manage their diabetes, we hope to develop services that help us to improve the life of patients who are having difficulties in living with their diabetes.

10. What if something goes wrong?

As we have said before, if taking part in this research project distresses you, or your child, you should let us know by using the contact information at the end of this sheet. In the first instance we will discuss your difficulties with you. If you need professional help, we will speak to you about this and you may then want to contact your GP or Doctor at clinic.

There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you, or your child, have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

11. Will my taking part in this study be kept confidential?

All information which is collected about you and your son/daughter in the course of the research will be kept strictly confidential. The information that you and your son/daughter provide will have names and addresses removed and replaced by a code number so that neither you or your son/daughter can be recognised from it. The information you provide will be stored in a locked filing cabinet at the University of Birmingham. Dr. Arie Nouwen, the study leader, will ensure the security of the information you give. Only members of the research team led by Dr. Nouwen will have access to the information/data for analyses.

The answers which you provide to the questions will not be given or told to your son/daughter or partner or anyone else within your child's diabetes team. However, if we are concerned about your health or well-being or that of your son/daughter, we may have to speak with other professionals to find appropriate help, but we will always discuss this with you first.

12. What will happen to the results of the research study?

The results of this research may on completion be published in a scientific journal, but you will not be personally identified in any report/publication. We will inform everyone who took part through a summary of our findings

13. Who is organising and funding the research?

The research is organised by the School of Psychology of the University of Birmingham and the Universities of Coventry and Warwick. The study is being funded by the Clinical Psychology Programme of these two Universities. Your child's doctor is obtaining no fee for his/her assistance.

14. Who has reviewed the study?

This research has been reviewed by the Thames Valley Multi-centre Research Ethics Committee.

15. Contact for Further Information

If you decide to take part, you will be given this information sheet to keep, together with a copy of the signed consent form.

Thank you for reading this information. If you have any matters which may concern you, or further questions, you may speak to the Senior Researcher in charge of this project, Dr Arie Nouwen, on the following number: (0121) 414 7203, or to Ms. Heidi Gibbins, Trainee on the Clinical Psychology Doctorate Course at Coventry University on 024 7688 8328.

Thank you for taking part in this study.

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM (Parent of Young Person 17-18 yrs)

Title of Project: Investigating self care in adolescents with type 1 diabetes.
Name of Researchers: Dr. Arie Nouwen and Ms. Heidi Gibbins

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2003 (version 3) for the above study and have had the opportunity to ask questions.

☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected.

☐
3. I agree to take part in the above study.

☐
4. I agree that I can be contacted in one year to see if I am interested in answering the questions again.

☐

Name of Parent/Carer 1

Date

Signature

Name of Parent/Carer 2 (if appropriate)

Date

Signature

Name of Person taking consent (if different from researcher)

Date

Signature

Dr Arie Nouwen
Researcher

May 2003
Date

Signature

- Please tick preferred option:
- I would like the questionnaires to be posted for us to complete at home

☐
- I would like a researcher to telephone and arrange a home visit

☐
- I would like to complete the questionnaires at my next out-patient visit

☐

1 for patient; 1 for researcher; 1 to be kept with hospital notes

General Information – Young Person

1. Date of Birth: _____ Age: _____
Date Month Year
2. Sex: _____ Male _____ Female
3. How much do you weigh? _____ stone _____ lbs or
_____ kg
4. How tall are you? _____ ft _____ inches or
_____ metres
5. When were you originally diagnosed with diabetes? _____
6. How often have you been hospitalised during the past 6 months?
_____ times
7. How much exercise, on average, do you do per week? (in hours) _____
8. What is your treatment regimen? (please write briefly, detailing level of
insulin, diet advice provided, monitoring etc.)

9. On how many days, during the last seven days, did you have an alcoholic
drink?
0 1 2 3 4 5 6 7
not at all every day
10. During the last seven days, how many alcoholic drinks did you take?
0 1-3 4-6 7-9 10 or more

General Information - Parent

1. When was your child originally diagnosed with diabetes?

_____ (age in years and duration since diagnosis)
2. How often has your child been hospitalised during the past 6 months?

_____ times
3. What is your child’s treatment regimen? (please write briefly, detailing level of insulin, diet advice provided, monitoring etc.)

Following my dietary plan for diabetes

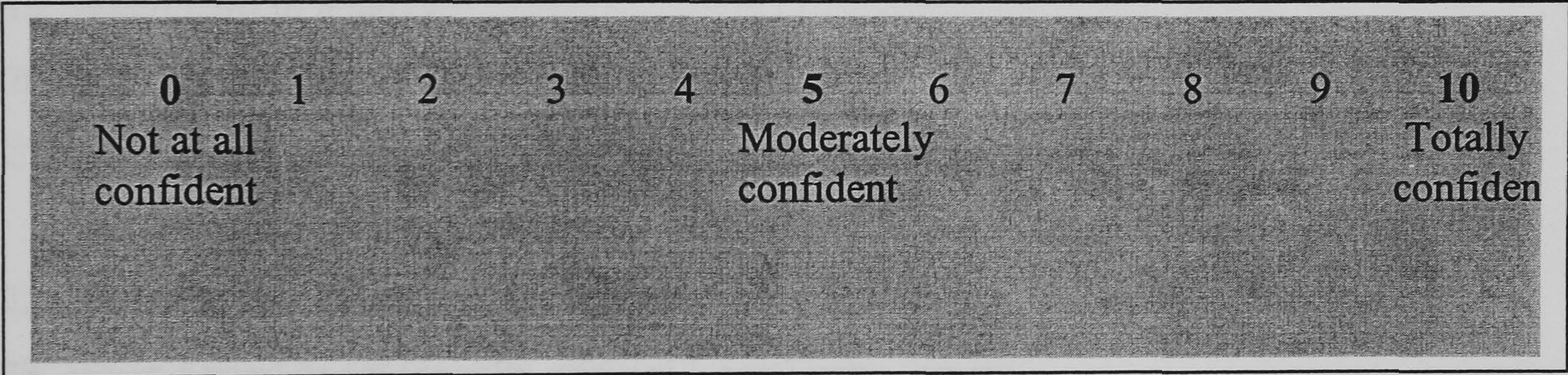
Sometimes its hard to following my dietary plan for diabetes, this happens in lots of situations. Some of these situations are listed in this questionnaire. We would like to know how confident you are that you will be able to regularly follow your dietary plan in these situations.

Using the scale below, please indicate how confident you are in your ability to follow your dietary plan on a regular basis by writing a number between 0 and 10 on the line provided. If the statement does not apply to your situation, please write N/A.

☺☺ Example: Going to the cinema with my friends. Confidence = 2

When I go to the cinema with my friends they buy lots of foods that are high in calories and sugar. I feel like buying the same foods. In that situation I am not very confident that I would not buy those foods.

If I always stick to my diabetes diet when I go with friends to the cinema, Confidence = 10.



	CONFIDENCE (0-10)
1. When watching television	_____
2. When feeling tired or bored	_____
3. When not at school and at home	_____
4. When feeling wound up or worried	_____
5. When seeing friends eating sugary foods	_____
6. When I am upset	_____
7. When eating out	_____
8. When feeling annoyed or angry	_____
9. When very hungry	_____
10. When feeling sad	_____

0	1	2	3	4	5	6	7	8	9	10
Not at all confident					Moderately confident					Totally confident

CONFIDENCE
(0-10)

- 11. When celebrating with others _____
- 12. When offered high calorie foods e.g. crisps, chips, biscuits _____
- 13. When lots of high calorie foods are available at home _____
- 14. When it is difficult to get hold of the foods I should
eat for my diabetes (fruit, vegetables, etc.) _____
- 15. When ill _____
- 16. When friends come around to my house _____
- 17. When on holiday _____
- 18. At parties, when foods that have high fat
and/or sugar content are offered to me _____
- 19. When I am in a hurry _____
- 20. When preparing my own meals _____
- 21. When faced with appealing foods that have high fat and/ or
sugar content in a supermarket or vending machines _____
- 22. When my life doesn't go to plan _____
- 23. When I need to eat (snacks, regular meals) even though
others are not eating _____
- 24. When feeling well _____
- 25. When I want more variety in my diet _____
- 26. When craving for high calorie foods _____

Following a dietary plan for diabetes

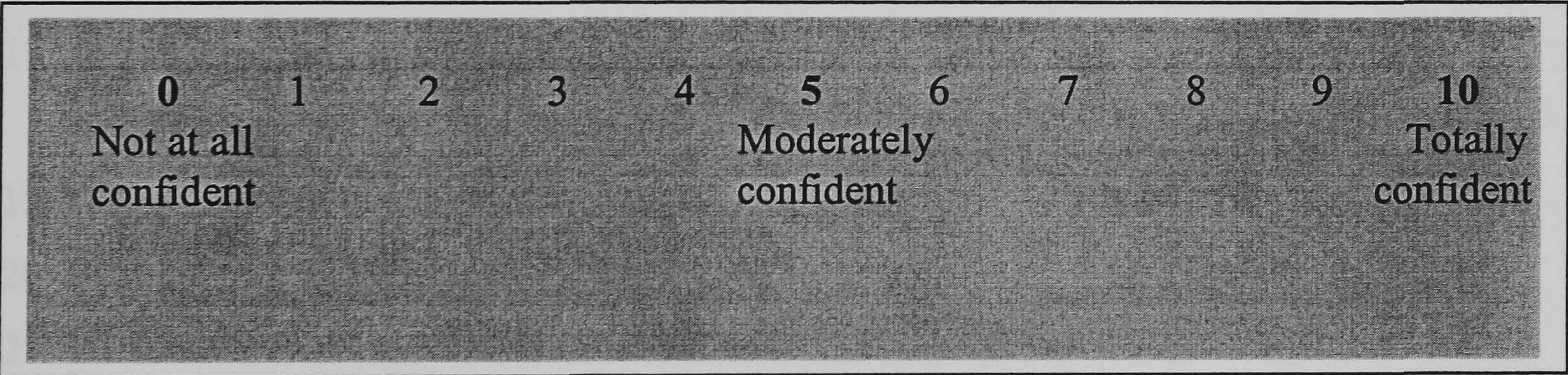
Sometimes it's hard for young people to follow their dietary plan for diabetes, this happens in lots of situations. Some of these situations are listed in this questionnaire. We would like to know how confident you are that your child would be able to regularly follow his/her dietary plan in these situations.

Using the scale below, please indicate how confident you are in your child's ability to follow his/her dietary plan on a regular basis by writing a number between 0 and 10 on the line provided. If the statement does not apply to your child's situation, please write N/A.

☺☺ Example: Going to the cinema with friends.

When my child goes to the cinema with his/her friends, they buy lots of foods that are high in calories and sugar. My child feels like buying the same foods. In that situation I am not very confident that my child would not buy those foods. Confidence = 2

If my child always sticks to his/her diabetes diet when he/she goes with friends to the cinema, Confidence = 10.



CONFIDENCE
(0-10)

- 1. When watching television _____
- 2. When feeling tired or bored _____
- 3. When not at school and at home _____
- 4. When feeling wound up or worried _____
- 5. When seeing friends eating sugary foods _____
- 6. When feeling upset _____
- 7. When eating out _____

0	1	2	3	4	5	6	7	8	9	10
Not at all confident				Moderately confident				Totally confident		

CONFIDENCE
(0-10)

8. When feeling annoyed or angry
9. When very hungry
10. When feeling sad
11. When celebrating with others
12. When offered high calorie foods e.g. crisps, chips, biscuits
13. When lots of high calorie foods are available at home
14. When it is difficult to get hold of the foods he/she should eat for his/her diabetes (fruit, vegetables, etc.)
15. When ill
16. When friends come around to the house
17. When on holiday
18. At parties, when foods that have high fat and/or sugar content are offered to him/her
19. When he/she is in a hurry
20. When preparing thier own meals
21. When faced with appealing foods that have high fat and/ or sugar content in a supermarket or vending machines
22. When his/her life doesn't go to plan
23. When he/she needs to eat (snacks, regular meals) even though others are not eating
24. When feeling well
25. When wanting more variety in his/her diet
26. When craving for high calorie foods

Diabetes Social Support Questionnaire - Family version - Adapted

Below are some statements about activities with which you may receive some support from your family. Using the scales below, firstly indicate how often the family member carries out the activity, and secondly, how this makes you feel (or how supportive you find this).

		-1	Not Supportive
0	Never	0	Neutral
1	Less than twice a month	1	A little supportive
2	Twice a month	2	Supportive
3	Once a week	3	Very Supportive
4	Several times a week		
5	At least once a day		
How often does a family member?		How does this make you feel?	

MEALS

Encourage you to eat the right foods?	_____	_____
Let you know they understand how important it is for you to eat right?	_____	_____
Ask if certain foods are okay for you to eat, before serving them?	_____	_____
Do the grocery shopping for your meals?	_____	_____
Schedule meals at the time you need to eat?	_____	_____
Remind you about sticking to your meal plan?	_____	_____
Suggest foods you can eat on your meal plan?	_____	_____
Join you in eating the same foods as you?	_____	_____
Get on your case after you ate something you shouldn't?	_____	_____
Avoid tempting you with foods or drinks that you shouldn't have?	_____	_____
Watch what you eat to make sure that you eat the right foods?	_____	_____
Cook meals for you that fit your meal plan?	_____	_____
Choose restaurants that serve food you can eat?	_____	_____
Eat at the same time you do?	_____	_____
Praise you for following your diet?	_____	_____
Tell you when you've eaten too much or too little?	_____	_____

			-1	Not Supportive
			0	Neutral
			1	A little supportive
			2	Supportive
			3	Very Supportive
0	Never			
1	Less than twice a month			
2	Twice a month			
3	Once a week			
4	Several times a week			
5	At least once a day			
How often does a family member?			How does this make you feel?	

Show they're pleased when you've eaten right?	_____	_____
Keep track of your meal plan for you?	_____	_____
Buy special foods that you can eat?	_____	_____
Tell you not to eat something you shouldn't?	_____	_____

Diabetes Social Support Questionnaire - Friends version - Adapted

Below are some statements about activities with which you may receive some support from your friends. Using the scales below, firstly indicate how often your friends carry out the activity, and secondly, how this makes you feel (or how supportive you find this).

0	Never	-1	Not Supportive
1	Less than twice a month	0	Neutral
2	Twice a month	1	A little supportive
3	Once a week	2	Supportive
4	Several times a week	3	Very Supportive
5	At least once a day		
How often does a friend?		How does this make you feel?	

MEALS

Encourage you to eat the right foods?	_____	_____
Let you know they understand how important it is for you to eat right?	_____	_____
Ask if certain foods are okay for you to eat, before serving them?	_____	_____
Schedule meals at the time you need to eat?	_____	_____
Remind you about sticking to your meal plan?	_____	_____
Suggest foods you can eat on your meal plan?	_____	_____
Join you in eating the same foods as you?	_____	_____
Get on your case after you ate something you shouldn't?	_____	_____
Avoid tempting you with foods or drinks that you shouldn't have?	_____	_____
Watch what you eat to make sure that you eat the right foods?	_____	_____
Eat at the same time you do?	_____	_____
Buy special foods that you can eat?	_____	_____
Tell you not to eat something you shouldn't?	_____	_____

IDENTIFYING YOUR PROBLEM AREAS IN DIABETES - TEEN VERSION
(PAID-T) (Short Form – Modified)

Name:_____ Age:_____ Sex: M__ F __

How old were you when your diabetes was diagnosed?_____

Today’s date _____

DIRECTIONS: Living with diabetes can sometimes be difficult. In day-to-day life, there may be many problems and hassles with your diabetes. The problems may range from minor hassles to major life difficulties. Listed below are a variety of possible problem areas which people with diabetes may have. Think about how much each of the items below may have upset or bothered you **DURING THE PAST MONTH** and circle the appropriate number.

Please note that we are asking you how much each item may be bothering you in your life, **NOT** whether the item is merely true for you. If you feel that an item is not a bother or a problem for you, you would circle “1”. If it very bothersome to you, you would circle “6”.

	not a problem		moderate problem		serious problem	
1. Not having clear and specific goals for my diabetes care	1	2	3	4	5	6
2. Feeling discouraged with my diabetes treatment plan	1	2	3	4	5	6
3. Feeling scared when I think about living with diabetes	1	2	3	4	5	6
4. Uncomfortable social situations relating to my diabetes care e.g. people telling me what to eat	1	2	3	4	5	6
5. Feeling of deprivation regarding food and meals	1	2	3	4	5	6
6. Feeling depressed when I think about living with diabetes	1	2	3	4	5	6
7. Not knowing if my mood or feelings are related to my diabetes	1	2	3	4	5	6
8. Feeling overwhelmed by my diabetes	1	2	3	4	5	6
9. Worrying about low blood sugar reactions	1	2	3	4	5	6
10. Feeling angry when I think about living with diabetes	1	2	3	4	5	6
11. Feeling constantly concerned about food and eating	1	2	3	4	5	6
12. Worrying about the future and the possibility of serious complications.	1	2	3	4	5	6
13. Feeling of guilt or anxiety when I get off track with my diabetes management.	1	2	3	4	5	6
14. Not “accepting” my diabetes.	1	2	3	4	5	6

	not a problem		moderate problem		serious problem	
15. Feeling unsatisfied with my diabetes doctor.	1	2	3	4	5	6
16. Feeling that diabetes is taking up too much of my mental and physical energy every day	1	2	3	4	5	6
17. Feeling alone with my diabetes.	1	2	3	4	5	6
18. Feeling that my friends and family aren't supportive of my diabetes management efforts	1	2	3	4	5	6
19. Coping with the complications of my diabetes	1	2	3	4	5	6
20. Feeling "burned out" by the constant effort needed to manage my diabetes.	1	2	3	4	5	6

IDENTIFYING YOUR CHILD’S PROBLEM AREAS IN DIABETES
(CPAID) – Adapted

ID: _____ Age: _____ Sex: M__ F__

How old was your child when they were diagnosed with diabetes? _____

Today’s date _____

DIRECTIONS: Living with diabetes can sometimes be difficult. In day-to-day life, there may be many problems and hassles with your child’s diabetes. The problems may range from minor hassles to major life difficulties. Listed below are a variety of possible problem areas which people who care for children with diabetes may have. Think about how much each of the items below may have upset or bothered you **DURING THE PAST MONTH** and circle the appropriate number.

Please note that we are asking you how much each item may be bothering you in your life, **NOT** whether the item is merely true for you. If you feel that an item is not a bother or a problem for you, you would circle “1”. If it very bothersome to you, you would circle “6”.

	not a problem		moderate problem		serious problem	
1. Not having clear and specific goals for my child’s diabetes care.	1	2	3	4	5	6
2. Feeling discouraged with my child’s diabetes treatment plan	1	2	3	4	5	6
3. Feeling scared when I think about my child living with diabetes	1	2	3	4	5	6
4. Uncomfortable social situations relating to my child’s diabetes care e.g. people telling them what to eat	1	2	3	4	5	6
5. Worrying that my child feels deprived regarding food and meals	1	2	3	4	5	6
6. Feeling depressed when I think about my child living with diabetes	1	2	3	4	5	6
7. Not knowing if my child’s mood or feelings are related to their diabetes	1	2	3	4	5	6
8. Feeling overwhelmed by my child’s diabetes	1	2	3	4	5	6
9. Worrying about my child having low blood sugar reactions	1	2	3	4	5	6
10. Feeling angry when I think about my child living with diabetes	1	2	3	4	5	6
11. Feeling constantly concerned about my child’s food and food and eating	1	2	3	4	5	6
12. Worrying about the future and the possibility of my child having serious complications.	1	2	3	4	5	6

	not a problem		moderate problem		serious problem	
13. Feelings of guilt or anxiety when my child gets off track with his / her diabetes management.	1	2	3	4	5	6
14. Not “accepting” my child’s diabetes.	1	2	3	4	5	6
15. Feeling unsatisfied with my child’s diabetes doctor.	1	2	3	4	5	6
16. Feeling that my child’s diabetes is taking up too much of my mental and physical energy every day	1	2	3	4	5	6
17. Feeling alone with my child’s diabetes.	1	2	3	4	5	6
18. Feeling that my friends and family aren’t supportive of my efforts to help my child manage his / her diabetes	1	2	3	4	5	6
19. Coping with the complications of my child’s diabetes	1	2	3	4	5	6
20. Feeling “burned out” by the constant effort needed to manage my child’s diabetes.	1	2	3	4	5	6

Diabetes Self-Care Activities Questionnaire – Adapted

The questions below ask about diabetes self-care activities during the past 7 days. If you were ill during the past 7 days, please think back to the last 7 days that you were not ill. Please answer the questions as honestly and accurately as you can.

(1) How often did you follow your recommended healthy eating plan over the last 7 days? (If you have not been given a specific healthy eating plan by the diabetes team, please answer using the general guidelines you have been given).

Always	Usually	Sometimes	Rarely	Never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(2) If you follow a basal bolus plan answer (a), if you follow a twice-daily injection plan answer (b):

(a) How often did you alter your fast acting insulin (Actrapid) according to your meal portion?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(b) How often did you eat erratically / haphazardly?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(3) During the past week, how many of your meals included starchy foods, such as cereals, pasta, rice, potatoes and bread?

None of them	A little of them	Some of them	Most of them	All of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(4) During the past week, how many of your meals including high fat foods, such as butter, cheese, oil, nuts, mayonnaise, fried food, salad dressing, crisps, pies, pizzas and sausages?

None of them	A little of them	Some of them	Most of them	All of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(5) During the past week, how many of your meals included sweets and desserts, such as pastries, cake, soft drinks (not diet), chocolate and cream biscuits?

None of them	A little of them	Some of them	Most of them	All of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(6) How many of your recommended insulin injections / medication did you take in the last 7 days that you were supposed to?

All of them	Most of them	Some of them	None of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(7) How many of your recommended insulin injections / medication did you have at the time you were supposed to?

All of them	Most of them	Some of them	None of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Diabetes Self-Care Activities Questionnaire – Adapted
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The questions below ask about your child's diabetes self-care activities during the past 7 days. If your child was ill during the past 7 days, please think back to the last 7 days that they were not ill. Please answer the questions as honestly and accurately as you can.

- (1) How often did your child follow their recommended healthy eating plan over the last 7 days? (If they have not been given a specific healthy eating plan by the diabetes team, please answer using the general guidelines you have been given).

Always	Usually	Sometimes	Rarely	Never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (2) If your child follows a basal bolus plan answer (a), if your child follows a twice-daily injection plan answer (b):

- (a) How often did your child alter his/her fast acting insulin (Actrapid) according to their meal portion?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (b) How often did your child eat erratically / haphazardly?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (3) During the past week, how many of your child's meals included starchy foods, such as cereals, pasta, rice, potatoes and bread?

None of them	A little of them	Some of them	Most of them	All of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (4) During the past week, how many of your child's meals including high fat foods, such as butter, cheese, oil, nuts, mayonnaise, fried food, salad dressing, crisps, pies, pizzas and sausages?

None of them	A little of them	Some of them	Most of them	All of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (5) During the past week, how many of your child's meals included sweets and desserts, such as pastries, cake, soft drinks (not diet), chocolate and cream biscuits?

None of them	A little of them	Some of them	Most of them	All of them
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

☐☐☐☐☐

(6) How many of your child’s recommended insulin injections / medication did he/she take in the last 7 days that he/she was supposed to?

All of
them

Most of
them

Some of
them

None of
them

☐☐☐☐

(7) How many of your child’s recommended insulin injections / medication did they have at the time they were supposed to?

All of
them

Most of
them

Some of
them

None of
them

☐☐☐☐

Diabetes Family Responsibility

For each of the following parts of your child's diabetes care, choose the number of the answer that best describes the way you handle things at home.

1—Child takes or initiates responsibility for this almost all of the time.

2—Parent(s) and child share responsibility for this about equally.

3—Parent(s) take or initiate responsibility for this almost all of the time.

	Responsibility		
	Child	Equal	Parent
	1	2	3
1. Remembering day of clinic appointment.			
2. Telling teachers about diabetes.			
3. Remembering to take morning or evening insulin injection/bolus by pump.			
4. Making appointments with dentists and other doctors.			
5. Telling relatives about diabetes.			
6. Taking more or less insulin according to results of blood sugar monitoring.			
7. Noticing differences in health, such as weight changes or signs of an infection.			
8. Deciding what to eat at meals or snacks.			
9. Telling friends about diabetes.			
10. Noticing the early signs of an insulin reaction.			
11. Giving insulin injections or boluses by pump.			
12. Deciding what should be eaten when family has meals out. (restaurants, friends' homes)			
13. Carrying some form of sugar in case of an insulin reaction.			
14. Explaining absences from school to teachers or other school personnel.			
15. Rotating injection sites or infusion set-ups for pump.			
16. Remembering times when blood sugar should be monitored.			
17. Checking expiration dates on medical supplies.			

COVENTRY UNIVERSITY - SCHOOL OF HEALTH AND SOCIAL SCIENCES

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: ALEX GIBBINS 2. Course: CLINICAL PSYCHOLOGY
(BLOCK CAPITALS)
3. Title of project: SELF MANAGEMENT CHALLENGES FOR ADOLESCENTS WITH TYPE 1 DIABETES AND THEIR FAMILIES.
4. Summary of the project in jargon-free language and in not more than 120 words:

Sample:

IS ADOLESCENTS WITH DIABETES AND THEIR PARENT/CAREGIVER.

Research site:

NORTHAMPTON GENERAL HOSPITAL.

Design (eg experimental):

QUALITATIVE APPROACH USING FOCUS GROUPS.

Methods of data collection:

FOLLOWING 'OPT IN' AND CONSENT TO PARTICIPATE IN THE STUDY PARTICIPANTS WILL BE INVITED TO TAKE PART IN A FOCUS GROUP. SEPARATE GROUPS WILL BE SCHEDULED FOR 'ADOLESCENTS WITH DIABETES' AND 'PARENTS OF ADOLESCENTS WITH DIABETES'.

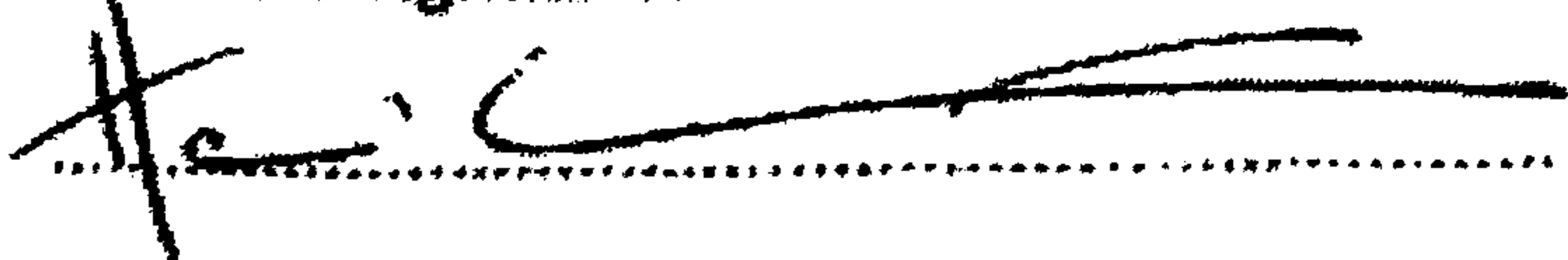
THE FOCUS GROUP WILL BE AUDIO-TAPED (CONSENT SOUGHT) AND TRANSCRIBED.

Access arrangements (if applicable):

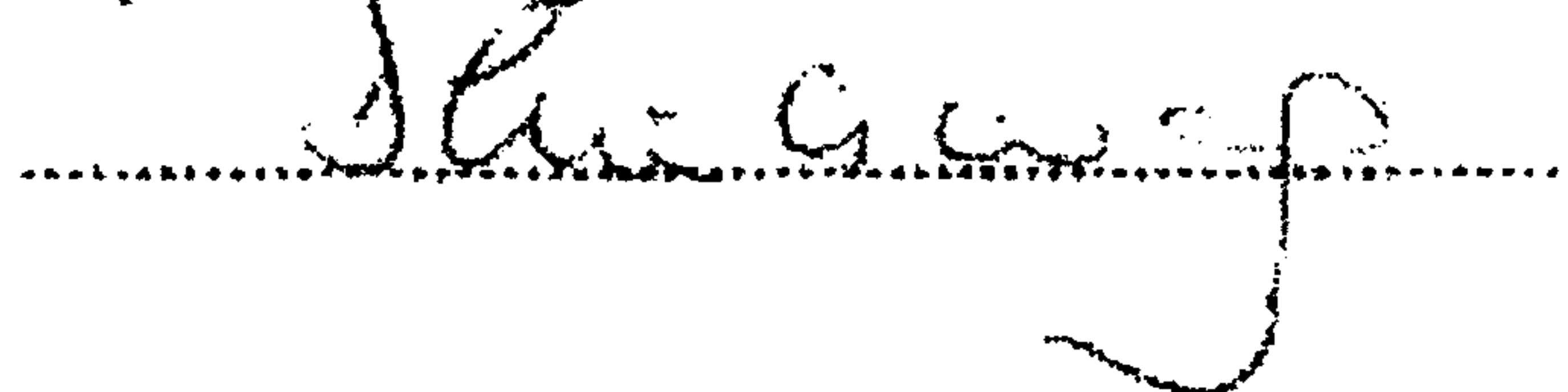
ACCESS VIA CONDUCTANT/PEDIATRIC SPECIALIST DOCTOR

- | | | |
|--|---|--|
| 5. Will the project involve patients(clients) and/or patient(client) data? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |
| 6. Will any invasive procedures be employed in the research? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 7. Is there a risk of physical discomfort to those taking part? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 8. Is there a risk of psychological distress to those taking part? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 9. Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 10. Is it intended to seek informed consent from each participant (or from his or her parent or guardian)? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |

Student's signature:



Supervisor's signature:



Date:

24/5/03

FOR COMMITTEE USE:

Immediate approval

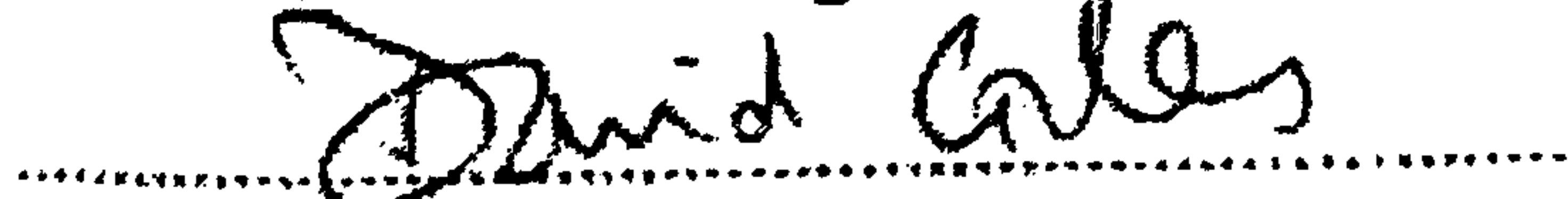
Referral to local Hospital Ethics Committee

☒
☐

Referral to full School Committee

Decision pending receipt of further information
(specify below)☐
☐

Committee Member's signature:



Date:

24/5/03

Northampton 

Primary Care Trust

Northampton Medical Research/Ethics Committee

Chairman: Dr Robin Sheppard

Administrator: Mrs Michelle Spinks ☎ (01604) 615363

Our Ref: RS/MS/03/25

8 April 2003

Ms Heidi Gibbins
120 Moorpark Road
West Heath
BIRMINGHAM
B31 4HE

Dear Ms Gibbins

03/25 Self-management challenges for adolescents with type 1 diabetes, and their families

The Chairman of the Northampton Medical Research/Ethics Committee has considered the amendments submitted in response to the Committee's earlier review of your application on 13 March 2003, as set out in our letter dated 17 March 2003. The documents considered were as follows:

- Letter from Heidi Gibbins to Dr Robin Sheppard dated 24 March 2003
- Consent form for audio recording of focus group (parent/carer)
- Consent form for audio recording of focus group (young person)
- Consent form for parent(s) and young person
- Sample letter of invitation/introduction
- Opt in form
- Information leaflet (young person)
- Information leaflet (parents/carers)

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am therefore pleased to confirm that Formal Ethical Approval has been granted.

I confirm that the Northampton Medical Research/Ethics Committee operates according to Good Clinical Research Practice (GCP) principles, and enclose a copy of the Committee's Constitutions and Standing Orders.

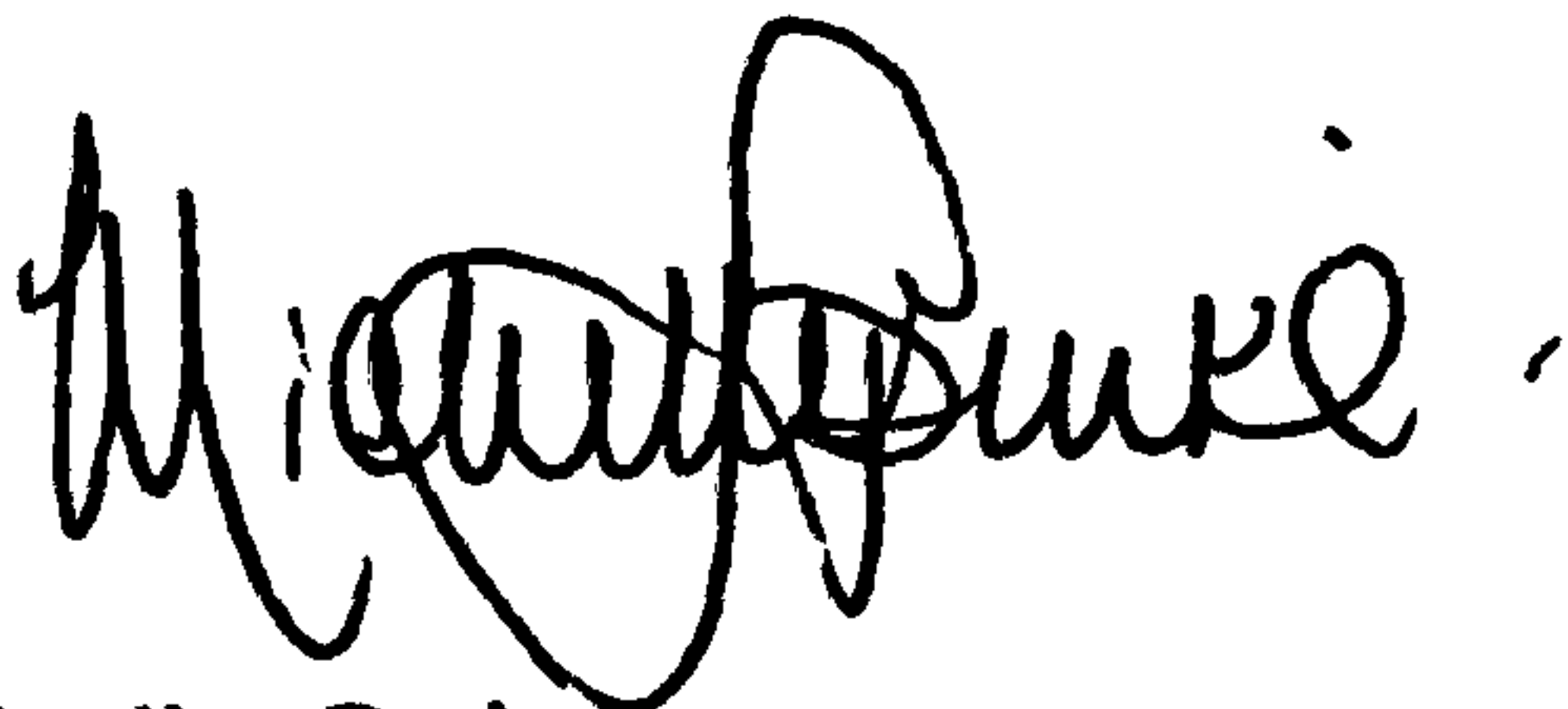
Before the study can proceed, it is your responsibility to seek Trust approval through the Research and Development office. Please contact Julie Wilson, R & D Manager, on Knightley Ward (Telephone: 01604 545941).

You will find details enclosed regarding a Regional funded project to record and analyse projects that have been submitted to this Ethics Committee. The letter enclosed explains the project in more detail. Please take time to read it, before completing the survey. Your participation is useful and necessary to the completion of a mapping exercise of research (any research) that is proposed, planned or taking part in Northamptonshire. Your record of using resources would be helpful in shaping future funding of research and development in the county.

To complete our records regarding the project, please complete and return the form accompanying this letter.

Please let me know if the study has to be terminated or any ethical considerations arise which need to be discussed further by the Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Michelle Spinks', with a stylized, cursive script.

Michelle Spinks
Administrator, Northampton Medical Research/Ethics Committee

Northampton General Hospital

NHS Trust

Paediatric Department
Northampton General Hospital
Billing Road
Northampton
NN1 5BD
Direct Line 01604 544591
Main Switchboard 01604 634700
Fax 01604 545640
E-mail: fran.ackland@ngh.nhs.uk

Date: 14th April 2003

Dear Patient / Carer,

Re: Self management challenges for adolescents with type 1 diabetes, and their families.

A research study is being carried out at this clinic by Heidi Gibbins:

This study has been designed to identify the challenges or difficulties a young person faces in managing their diabetes. Patients and their Carers (Parents) are being asked to attend a 'Focus Group' to talk about their thoughts, feelings and experiences of managing the diabetes.

As you are currently being treated at this hospital for diabetes, the responses of you and your family would be very valuable. It is hoped that the results of this study will help other health care staff understand the needs of their patients and consequently improve services.

If you would like to take part in this study, details of which are given on the information leaflet enclosed, please complete the reply slip enclosed with this letter and return it to the Diabetes team. The researcher will then contact you to arrange a convenient time to attend a Focus Group.

I would like to thank you for taking time to read this letter and hope to hear from you soon. If you have any queries, please feel free to contact the researchers or myself on the telephone numbers given.

Yours sincerely

Dr Fran Ackland
Consultant Paediatrician



Study title: **Self-management challenges for adolescents with type 1 diabetes, and their families.**

- I am interested in taking part in the above study and agree to the researchers contacting me:
- I understand that I am under no obligation to take part in the study

Name:

Address:
.....
.....

Telephone No:

Date:

Please return to the diabetes clinic in the envelope provided.

Thank you for your reply. As we may receive more responses than we can manage, it is possible you may not be invited to participate.

Researchers Contact Details

**Heidi Gibbins
Trainee Clinical Psychologist
Clinical Psychology Doctorate Course
School of Health and Social Sciences
Coventry University
Coventry
024 7688 8328 / 07958 714129 (Out of hours)**

Northampton General Hospital

NHS Trust

Paediatric Department
Northampton General Hospital
Billing Road
Northampton
NN1 5BD
Direct Line 01604 544591
Main Switchboard 01604 634700
Fax 01604 545640
E-mail: fran.ackland@ngh.nhs.uk

Information Leaflet (Young Person)

Self-management challenges for adolescents with type 1 diabetes, and their families.

Introduction to the research & an invitation to take part.

You are being invited to take part in a research study. This invitation has also been extended to your parent / carer.

We want to learn all about the challenges or difficulties you face in managing your diabetes. To be sure that our findings represent our clients we are approaching a number of families to take part. We thank you for taking the time to read this leaflet before considering whether you would like to take part in this study.

What is the research about?

The study is about finding out what you need to help you to cope well with diabetes. We want to find out what things are difficult for you, and what things are more manageable.

What will I be asked to do?

If you decide to take part, you will be invited to a special group meeting, called a Focus Group. This invitation will also be extended to your parent who would attend a different meeting. The group will consist of 7-8 similarly aged young people with diabetes, and the researcher. The meeting will take place at Northampton General Hospital and will last about an hour.

During the meeting, you will be asked about your thoughts, feelings and experiences of managing your diabetes. You are invited to comment on other peoples experiences and share your own ideas. This group is all about your views, and in order to respect confidentiality (privacy), you are reminded that all information discussed in the group should not be talked about outside of the group.

The meeting will be tape recorded so that the information can be reviewed by the researcher at another time.

What are the benefits?

There are no direct benefits for you. However, by learning about the views and experiences young people and their families have of managing their diabetes, services can be developed to monitor and meet your needs most effectively.

What are the risks?

There are no physical risks involved. If it reveals any problems that you were previously unaware of, we will ensure that appropriate support is available to help you.

What if I do not want to take part?

Taking part is entirely voluntary. Your decision will not affect your treatment in any way. You are free to withdraw from the study at any time.

What happens to the information?

The dialogue (talking) on the tapes will be examined and the findings presented and published in papers to help other health care staff understand the issues. All information will be kept anonymous.

The information you give us will be kept confidential by the researchers. It will not be given to anyone else within the diabetes team (like doctors or nurses). However, if anything is said which gives the researcher particular concern, for either your welfare or your parents', appropriate people (like your doctor) will be informed. If this happens we will tell you about any action taken.

Who else is taking part?

Other families with a child with type I diabetes, who is aged 12-16, under the care of the paediatric diabetes team at Northampton General Hospital are being invited to take part.

What happens at the end of the research study?

At the end of the study a summary of our findings will be given to everyone who took part.

What if I have more questions or do not understand something?

If you have any questions about the study or anything in this leaflet, do not hesitate to contact the person named below (main researcher).

What happens now if I decide to take part?

If you decide that you want to take part, return the consent form to the diabetes team. We will then contact you to arrange a time to meet.

What happens if I change my mind during the study?

If you change your mind at any point you can leave the study and any information you have already given will be destroyed. This will not affect your treatment in any way.

Contact details:

Heidi Gibbins
Clinical Psychologist in Training
Clinical Psychology Doctorate Course
School of Health and Social Sciences
Coventry University
Priory Street, Coventry
024 7688 8328 (Office hours) / 07958 714129 (Out of Hours)

Northampton General Hospital

NHS Trust

Paediatric Department
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Billing Road
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NN1 5BD
Direct Line 01604 544591
Main Switchboard 01604 634700
Fax 01604 545640
E-mail: fran.ackland@ngh.nhs.uk

Information Leaflet (Parents/Carers)

Self-management challenges for adolescents with type 1 diabetes, and their families.

Introduction to the research & an invitation to take part.

You are being invited to take part in a research study. This invitation has also been extended to the young person to whom you offer support.

We want to learn all about the challenges or difficulties you face in managing your child's diabetes. To be sure that our findings represent our clients we are approaching a number of families to take part. We thank you for taking the time to read this leaflet before considering whether you would like to take part in this study.

What is the research about?

The study is about finding out what you need to help you to cope well with your child's diabetes. We want to find out what things are difficult for you, and what things are more manageable.

What will I be asked to do?

If you decide to take part, you will be invited to a special group meeting, called a Focus Group. This invitation will also be extended to your child who would attend a different meeting. The group will consist of 7-8 parents of similarly aged children, and the researcher. The meeting will take place at Northampton General Hospital and will last about an hour.

During the meeting, you will be asked about your thoughts, feelings and experiences of managing your child's diabetes. You are invited to comment on other peoples experiences and share your own ideas. This group is all about your views, and in order to respect confidentiality, you are reminded that all information discussed in the group should not be talked about outside of the group.

The meeting will be tape recorded so that the information can be reviewed by the researcher at another time.

What are the benefits?

There are no direct benefits for you. However, by learning about the views and experiences children and their families have of managing their diabetes, services can be developed to monitor and meet your needs most effectively.

What are the risks?

There are no physical risks involved. If it reveals any problems that you were previously unaware of, we will ensure that appropriate support is available to help you.

What if I do not want to take part?

Taking part is entirely voluntary. Your decision will not affect your child's treatment in any way. You are free to withdraw from the study at any time.

What happens to the information?

The dialogue on the tapes will be examined and the findings presented and published in papers to help other health care staff understand the issues. All information will be kept anonymous.

The information you give us will be kept confidential by the researchers. It will not be given to anyone else within the diabetes team (like doctors or nurses). However, if any information arises which gives the researcher particular concern, for either child or parent welfare, appropriate people will be informed. In these circumstances you will be notified of any action deemed necessary.

Who else is taking part?

Other families with a child with type I diabetes, who is aged 12-16, under the care of the paediatric diabetes team at Northampton General Hospital are being invited to take part.

What happens at the end of the research study?

At the end of the study a summary of our findings will be given to everyone who took part.

What if I have more questions or do not understand something?

If you have any questions about the study or anything in this leaflet, do not hesitate to contact the person named below (main researcher).

What happens now if I decide to take part?

If you decide that you want to take part, return the consent form to the diabetes team. We will then contact you to arrange a time to meet.

What happens if I change my mind during the study?

If you change your mind at any point you can leave the study and any information you have already given will be destroyed. This will not affect your child's treatment in any way.

Contact details:

Heidi Gibbins
Clinical Psychologist in Training
Clinical Psychology Doctorate Course
School of Health and Social Sciences
Coventry University
Priory Street, Coventry

~~024 7688 8328~~ (Office hours) / 07958 714129 (Out of Hours)

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Fax 01604 545640
E-mail: fran.ackland@ngh.nhs.uk

Consent Form for Parent(s) and Young Person

Child's Surname	
Child's other name(s)	
Date of Birth	
Consultant	

Name of Research Project:
Self-management challenges for adolescents with type 1 diabetes, and their families.

The aim of this project is to:
Help us to find out what things help young people and their families manage type I diabetes well, and what things make this more difficult.

The benefits are:
There are no direct benefits for you. However, it will help us to develop services which can meet families' needs appropriately and increase the knowledge of these management issues for diabetes care amongst other health care staff.

The risks are:
There are no physical risks involved in this study and the decision to take part or not to take part will not affect your child's treatment in any way.

To be completed by Clinician / Nurse / Researcher

I confirm that I have explained the study to the parent(s) and young person and ensured that they have received the information leaflet.

NAME (Print)	Position	Date
Signature		

To be completed by Parent and Young Person

If you have any further questions, ask the researcher. You can change your mind at any time, even if you have signed this form.

I agree

To be contacted by the researcher in order to arrange a suitable meeting time for me and my child to participate in this study.
That I have read the information leaflet explaining this study.
That if I do take part in this study and attend a Focus Group, further consent will be taken prior to the use of any audio-recording equipment.

I understand

that I can leave the study at any time.

NAME (Young Person)	Signature	Date
NAME (Parent)	Signature	Date

POSITIVE ABOUT
DISABILITY

PEOPLE

Questions – Young Person session

Tell us your name, for how long you've had diabetes, and what you most enjoy doing when you're not working or at school.

When you hear the words diabetes, and self management, what comes to mind?

Think back over the past few years. How have you learnt to follow the advice given for dietary self care and insulin administration?

Why do you do it? (What has motivated you to follow the advice?)
(Cues: Health, Friends, Family, Advice, other reasons)

What is most important? Which of those mentioned was most influential?

Tell us the things that get in the way and make you not follow the advice.

Some people have said that friends and family can make it easier to manage their diabetes. How is this for you? What role do others have in your success?...and who is most helpful (Cues: Friends, Family, Nurses)

How do you make sure you get the support you need?

What gets in the way or makes it difficult to access this support?

We are trying to help young people with diabetes follow their self management program. What advice do you have for us?

Our purpose today was to understand what makes it difficult, and what makes it easier, to manage your diabetes. We also wanted to know how the support of others affects this. Have we missed anything?

Questions – Parent session

Tell us your name, for how long your child has had diabetes, and one thing you'd like us to know about your child – one thing that your child does that makes you smile?

When you hear the words diabetes self management, what comes to mind?

Think back over the past few years. How have you learnt to support your child in following the advice given for dietary self care and insulin administration? (Cues: Is it easy to support them? Are you still involved?)

What has motivated you to help them follow this advice?
(Cues: Family, Friends, Medical advice, Physical Health, Personal desire to change)

Which of those mentioned was most influential?

Tell us the things that get in the way and make it difficult to follow the regime.

Accessing support from friends and family can make it easier for you to help manage your child's diabetes. Is this how you see it? What role do others have in your success? What role do others have in your child's success?

How do you make sure you get the support you need?

What can make it difficult to access this support?

We are trying to help young people with diabetes follow their self management program. What advice do you have for us?

Our purpose today was to understand what makes it difficult, and what makes it easier, for young people and their families to manage diabetes. We also wanted to know how the support of others affects this. Have we missed anything?

Northampton General Hospital

NHS Trust

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 NN1 5BD
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 Fax 01604 545640
 E-mail: fran.ackland@ngh.nhs.uk

Consent Form for Audio recording of Focus Group (Young Person)

Name of Research Project

Self-management challenges for adolescents with type 1 diabetes, and their families.

Aims

To find out what things help young people and their families manage diabetes well and what things make this more difficult.

Details of Audio recording

- This Focus group will be recorded using Audiotape
- These recordings will be used only as part of the research study.
- After completion of this study, the recordings will be destroyed.
- All information from this meeting will be kept confidential by the researcher. It will not be given to anyone else within the diabetes team (like Doctors or Nurses). However, if any information arises which gives the researcher particular concern, for either child or parent welfare, this will be shared with the appropriate people (like your Doctor).
- All information from this meeting will remain anonymous (not have your name on it)
- If you want to withdraw or vary your consent at any time (decide you do not want to take part), the recording will not be used and will be erased as soon as possible.

To be completed by Researcher

I confirm that I have explained the recording procedure to the young person and ensured that they have had the opportunity to ask questions.

NAME (Print)

Position

Date

Signature

To be completed by Young Person and Parent

If you have any further questions, ask the researcher. You can change your mind at any time, even if you have signed this form.

I agree That I have read the information explaining the use of audiotape recording for this Focus Group.

To participate in the Focus Group.

I understand That I can leave the study at any time / withdraw consent

NAME (Young Person)

Signature

Date

NAME (Parent)

Signature

Date



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Consent Form for Audio recording of Focus Group
(Parent/Carer)

Name of Research Project

Self-management challenges for adolescents with type 1 diabetes, and their families.

Aims

To find out what things help young people and their families manage diabetes well and what things make this more difficult.

Details of Audio recording

- This Focus group will be recorded using Audiotape
- These recordings will be used only as part of the research study.
- After completion of this study, the recordings will be destroyed.
- All information from this meeting will be kept confidential by the researcher. It will not be given to anyone else within the diabetes team. However, if any information arises which gives the researcher particular concern, for either child or parent welfare, this will be disclosed to the appropriate people.
- All information from this meeting will remain anonymous (not have your name on it)
- If you want to withdraw or vary your consent at any time, the recording will not be used and will be erased as soon as possible.

To be completed by Researcher

I confirm that I have explained the recording procedure to the parent and ensured that they have had the opportunity to ask questions.

NAME (Print)	Position	Date
--------------	----------	------

Signature

To be completed by Parent

If you have any further questions, ask the researcher. You can change your mind at any time, even if you have signed this form.

I agree	That I have read the information explaining the use of audiotape recording for this Focus Group.
I understand	To participate in the Focus Group.
	That I can leave the study at any time / withdraw consent

NAME (Parent)	Signature	Date
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IPA Stage 3 – Looking for connections

Example using Parent Focus Group transcript

Theme	Transcript
Blame	P17 L1 “well I’ve been very stupid, I haven’t joined”
Guilt	P17 L9 “I felt very guilty about it”
Being punished	P17 L9 “you feel like saying “Have I done something wrong”
Shame	P10 L12 “I can’t be there to prepare things for her all the time”
Uncertainty	P3 L1 “there’s no book there saying this is right, that’s the hardest part actually”
Sadness	P1 L4 “you know it still upsets me”
Shock	P2 L2 “it was a shock”
Anger	P15 L1 “the teacher was very apologetic but it shouldn’t have happened”
Frustration	P3 L1 “I can find it frustrating”
Burden	P17 L9 “you as a parent, it’s an extra burden”
Overwhelmed	P4 L9 “this is going nowhere”

IPA Stage 4 – A table of themes

Example using Parent Focus Group transcript

Themes	Transcript
Emotions	
Guilt	P17 L9 “I felt very guilty about it”
Blame	P17 L1 “well I’ve been very stupid, I haven’t joined”
Anxiety	P3 L1 “I worry more than she does”
Fears	P5 L5 “I don’t want it yo-yoing”
Anger	P15 L1 “the teacher was very apologetic but it shouldn’t have happened”
Frustration	P3 L1 “I can find it frustrating”
Burdened	P17 L9 “you as a parent, it’s an extra burden”
Overwhelmed	P4 L9 “this is going nowhere”
Parenting / Parenting role	
Caring for a teenager	P3 L1 “she’s a typical teenager”
Normalisation	P6 L1 “goes out to the cinema, sees her friends, goes to sleepovers”
Inclusion	P6 L1 “wants to wear all the latest things, and you don’t want to carry a bag around with you”
Caring for your child with diabetes	P4 L1 “I know what she should, and she knows what she should do”
Learning curve	P2 L1 “you learn, you know you learn a lot and I suppose it’s the best way really”
Knowledge	P7 L1 “I did a lot of reading”
Empathy	P18 L20 “they can be carefree but they have to think more”
Conflict	P14 L9 “you don’t want them to turn against it so they think “oomph” and they want to try to pretend they haven’t got it anymore”

IPA Stage 5 – Master list of themes

Example using Parent Focus Group transcript

Master themes	Sub-themes
Emotions	<i>Guilt</i>
	<i>Anger</i>
	<i>Anxiety</i>
	<i>Burdened</i>
Identity as a Parent	<i>Parenting a teenager</i>
	<i>Parenting a child with diabetes</i>
	<i>Conflict in parental role</i>
Role of others	<i>Peer support</i>
	<i>Wider awareness</i>
Balance	<i>Good enough</i>
	<i>Sharing responsibility</i>

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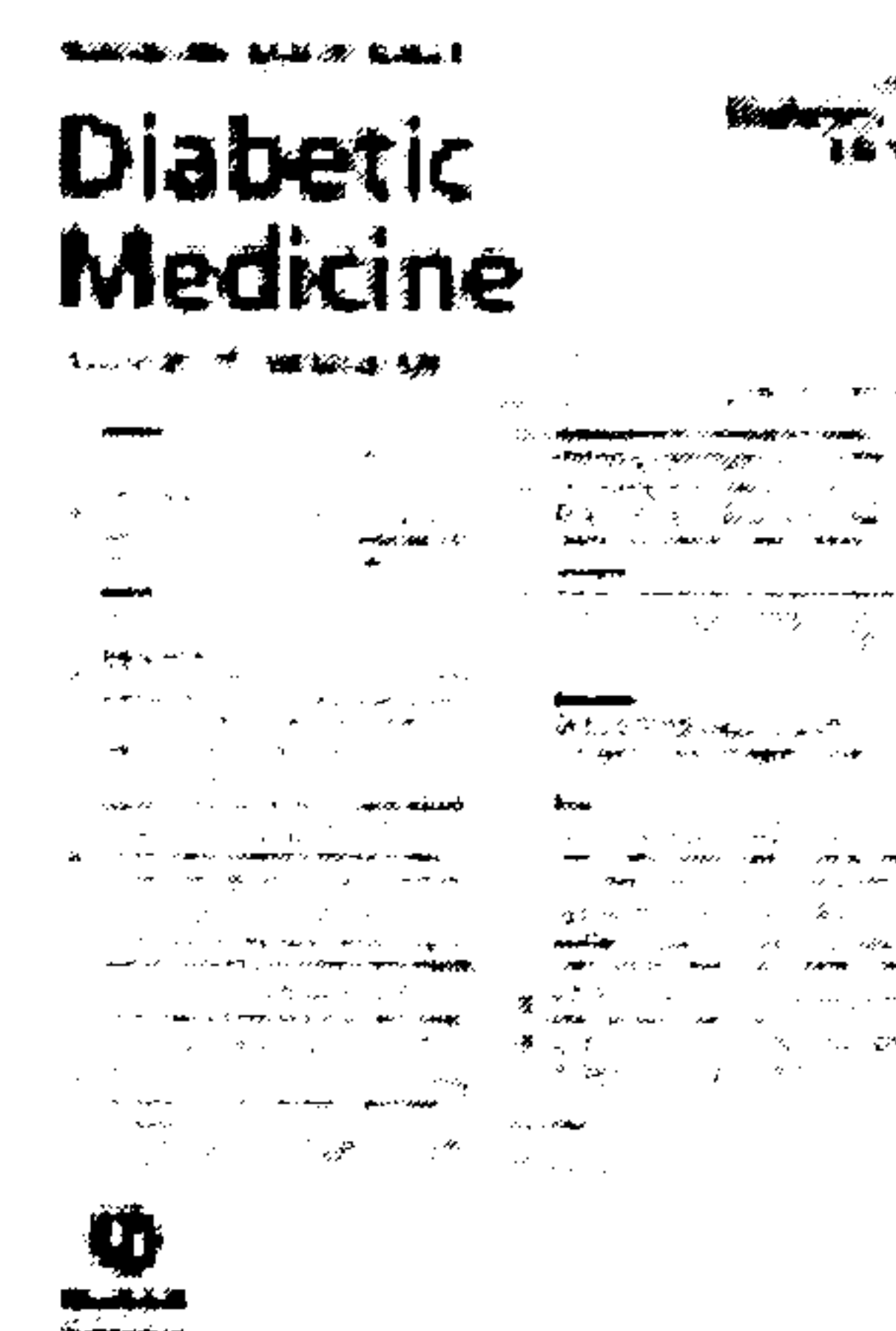
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Types of Article

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Original Articles Original research studies of relevance to diabetes mellitus science and practice. Clinical science and clinically relevant basic science papers will be considered. Suggested length 2500-3000 words.

Clinical Practice Original articles focusing on issues directly related to the clinical presentations and management of diabetes mellitus.

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Manuscripts are published from disk and must be provided in this form with the final accepted version of the manuscript. This reduces typesetting errors and speeds up publication. The final version of the hard copy and the file on disk must be the same. Carriage returns should not be used at the ends of lines within paragraphs. The hyphenation option should be turned off. Disks will not be returned to authors.

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Original articles should conform to the uniform requirements for manuscripts submitted to biomedical journals - the Vancouver style (*Br Med J* 1998; 296: 401-405) - as adopted by *Diabetic Medicine*. The layout should be divided conventionally into subsections, each starting on a new page.

Title page should include the title; authors (initials and surnames but without qualifications); authors' affiliations; name and full address of the author who will check proofs and deal with correspondence (with telephone, fax numbers and E-mail); a running title not exceeding 75 characters including spaces.

Second page A structured summary (no more than 250 words) should describe the content of the paper accurately and the important conclusions, couched in terms which will be understood by the majority of readers of the Journal. The main headings should be aims, methods, results, conclusions. A list of key words (no more than 5) should be given for reference purposes together with a list of abbreviations used.

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Footnotes should not be used except in tables.

References are only acceptable if already published or if formal acceptance has been given for publication when the journal title is followed by ('in press'); they are indicated in the text by bracketed numbers and listed in order of quotation in the text, and given in the Vancouver style, for example:

1. Klein R. The epidemiology of diabetic eye disease. In Pickup J, G Williams eds. *Textbook of Diabetes*, 2nd edn. Oxford: Blackwell Science 1997: 44:1-9
2. Sculpher MJ, Buxton MJ, Ferguson BA, Humphreys JE, Altman JFB, Spiegelhalter DJ *et al*. A relative cost-effectiveness analysis of different methods of screening for diabetic retinopathy. *Diabet Med* 1991; 8: 644-650.
3. Jarrett RJ. Insulin and hypertension (Letter). *Lancet* 1987; ii: 748-749.

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The following types of paper are invited :

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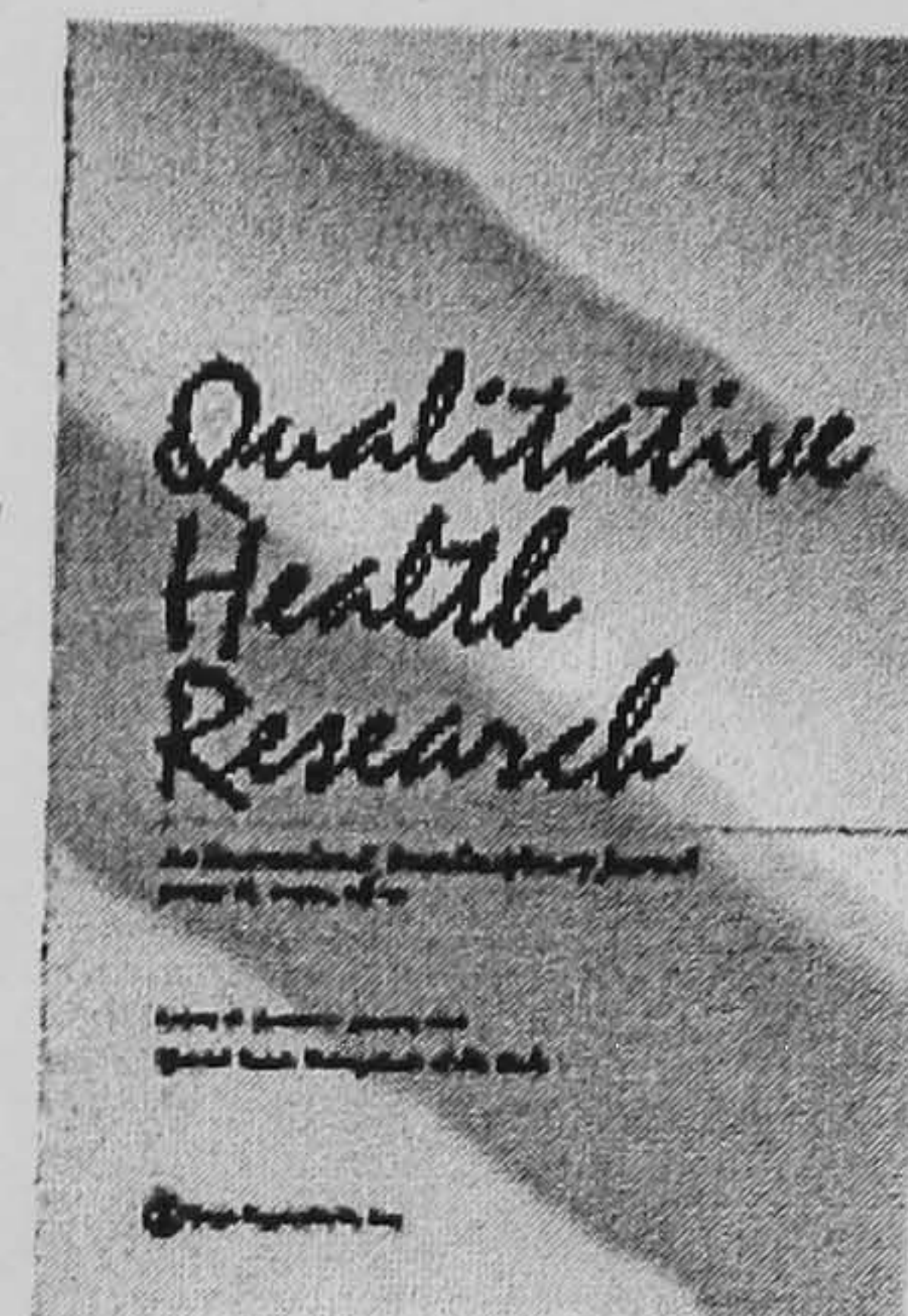
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- In the text, do not refer to your article as a "paper" - it is/will be an article.
- Avoid anthropomorphisms like "This article argues..."; rather, write "In this article, I argue..."
- Do not prepare a table listing participants and their demographic characteristics line by line. It is a threat to anonymity, and it will not be published. Describe participants as group data. For similar reasons, do not "tag" each quotation by participant, thereby linking the quotations throughout the article to a particular participant.

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